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ABSTRACT

Five papers from a 1980 conference on normalization reflect contemporary thinking about the principle's implication for mental retardation. G. Dybwad begins with "Normalization and Its Impact on Social and Public Policy," in which he cites progress in the popular attitude towards individuals with retardation. A panel discussion by S. Kaplan, V. Schaaf, and D. Heath, three members associated with a self help consumer group, focuses on "Normalization and the Consumer." P. Roos, in his paper "Normalization and Society," cites confusion over the term and identifies justifications for the normalization principle. C. Brown presents "Normalization and the Law" in which she considers legal issues in the protection of rights and institutional care. A final paper, "Normalization and Economics" by R. Conley and J. Noble, focuses on issues in community based care, employment, and government action. Participant discussions following the five papers are presented. (CL)

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Normalization Re-Examined

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Advancing Your Citizenship

Normalization Re-Examined

Proceedings of a National Conference on Normalization and Contemporary Practice in Mental Retardation

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January 1982

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Number 5

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This monograph is the result of a lot of creative thought and hard work by a number of people. The thought and work of the presenters and participants are evident in the pages which follow. I thank all of them for taking time from busy schedules to examine and deliberate the current state-of-the-art of services to mentally retarded and other developmentally disabled persons.

I also want to acknowldge eight people who helped conceptualize, plan, implement and sponsor both the conference and this monograph. These people were, like me, convinced of the need for a professional "time-out" in order to look at some important issues. The names of these people are shown below. I thank all of them very much; their contributions were significant.

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Introduction

Gilbert Foss

Normalization is a human service ideology directed toward preparing mentally retarded persons for physical and social integration into the community. The North American orientation to this system, which was first introduced in this country in the early 1970's, is reflected in the following definition:

> Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible. *(1, p. 28)*

Central to this definition are goals, principles, and suggested procedural guidelines for providing conditions which allow mentally retarded persons to live within the community as "normatively" as possible.

Over the past decade, the concept of normalization has become the adopted human services model for mentally retarded persons. Its philosophy has been translated into legislation, program policies, and procedures which are practiced throughout many professional agencies providing services for these persons. Indeed, professionals in the field of mental retardation, in both academic and service settings, have promoted a widespread acceptance of normalization.

We must be reminded that normalization is based upon a set of values and beliefs. The implementation of these values has had a pervasive impact on the lives of mentally retarded persons who often have relatively little choice but to abide by them. Thus, it is only proper that normalization be closely examined.

A small group of professionals and consumers was selected to attend a national conference in 1980 to formally address some of the major issues and implications of normalization and contemporary practice in mental retardation (see page 63 for a complete list of names of the conference participants and presenters). This monograph is a product of that conference. The program had three major purposes: (1) to examine the state-of-the-art of normalization in terms of its impact on social and public policy; (2) to address normalization in terms of major issues and their implications as they relate to the consumer, society, law, and economics; and (3) to provide program participants with a structured forum within which to examine these issues and their implications. This document contains the addresses of each of the presenters, and edited excerpts of the participant discussions.

The following four categories were identified as the major discussion foci for this conference: (1) the consumer, (2) society, (3) law, and (4) economics. The remainder of this **Introduction** presents each of these four areas in terms of the rationale for their inclusion and a sample of possible issues for discussion. This material in the form of a prospectus, was sent to all participants prior to the conference. In the final analysis, however, the invited presenters and participants generated what they considered to be the relevant issues within each area.

The Consumer

Wolf Wolfensberger, in his book **Normalization**, states that "... a (potentially) deviant person should be enabled to emit behaviors and an appearance appropriate (normative) within that culture for persons of similar characteristics, such as age and sex" *(1, p. 28)*. This premise, which is central to the North American normalization philosophy, says that certain (deviant) persons should conform both in behavior and appearance to the expectations of the dominant culture.

In essence, the practice of normalization involves the imposition of the values, beliefs, and behaviors of the dominant culture upon the mentally retarded person. An initial task of this institute is to explore the effects of this imposition of values as experienced by mentally retarded persons, primarily through their direct input.

A variety of issues and concerns can be raised in terms of this examination of the relationship between normalization philosophy/practice and the mentally retarded person to whom it is applied. A few of these are highlighted below:

1. How do mentally retarded persons view normalization practices as a means for assisting them to develop and maintain their own personal identity?
2. How do mentally retarded persons perceive normalization practices as a means for assisting them to establish and maintain social relationships?
3. How do mentally retarded persons perceive normalization practices as a means for assisting them to secure equal rights and protection under the law?
4. How do mentally retarded persons perceive normalization practices as a means for assisting them to become contributing members of the community?

Society

Normalization calls for the integration of mentally retarded people into society. Community integration is a very complicated process for the mentally retarded person in this complex and highly literate society, posing problems for both the person being normalized and this "non-retarded" society. Social service organizations have the most direct control over implementing normalization through treatment/rehabilitation/education programs. Mentally retarded persons feel the impact of such programming as they exercise their learned skills in society. In turn, society must respond to these persons being integrated, to the normalization programs serving them, and to the assumptions and premises behind normalization.

It is extremely important that we understand the implications of placing a mentally retarded person within a society which has traditionally been sheltered from his/her presence, as well as the knowledge of his/her existence. That is, teaching mentally retarded persons and society to accept and interact with one another calls forth some serious issues for consideration:

1. Is normalization philosophy/practice an effective means for integrating persons with mental retardation into the community?
2. What do we expect from society in terms of accepting and accommodating mentally retarded people?
3. Normalization, with its accent on service provider philosophy and practice, may have lessened the need and respect for parental opinion and involvement. How is normalization ideology and practice affecting the families of mentally retarded persons?

Law

The law, as interpreted by the courts and established in legislation, has a profound impact upon the way disabled persons are treated by society. Laws relating to accessibility and nondiscrimination, for example, reflect a social response to the handicapped. In addition, laws regarding individualized program planning, least restrictive environment, and procedural safeguards reflect what society is willing to contribute to the development and well-being of its handicapped citizens. Often the scope and operation of publicly supported services are a direct response to law.

In actual practice, however, the law may or may not support normalization. Some of the issues regarding the relationship between normalization and the legal system follow:

1. Should laws relating to incompetence and guardianship be modified, and if so, what would be the effect on retarded persons who may not be able to function adequately in this society?
2. Equal opportunities for mentally retarded persons generally have been interpreted to mean **more**, **better**, or **different** opportunities and services. Is this consistent with normalization?
3. Advocates for retarded persons frequently argue that this population is entitled to special protection from society. To what extent is special protection compatible with normalization principles and practices?

Economics

In 1970 alone, an estimated $4.7 billion was expended on selected programs serving persons with mental retardation. Since that time, citizen concern over taxation and inflation has created an ever increasing demand for limiting government spending. Thus, the professional community must now more closely examine the cost-effectiveness of the services advocated for handicapped persons. The following issues relate to the cost-effectiveness of the implementation of the normalization philosophy.

1. Do present community living alternatives balance both the normalization emphasis on independent living and cost-effectiveness concerns?
2. Is competitive employment a realistic and cost-effective goal for all mentally retarded persons?
3. Is normalization philosophy and practice the best (most cost-effective) vehicle for changing the image of the mentally retarded citizen from that of a passive recipient of social benefits to that of one who is a contributing member of society?

The remainder of this monograph contains the five presentations given at the national conference and edited excerpts of the participant discussion which followed four of them. Several points about the **Participant Discussion** sections bear mentioning. First, they are not inclusive of all issues raised at the conference. Rather, what appears represents the Editor's judgement regarding the most relevant and interesting topics discussed. Second, as the reader will quickly realize, many of the issues discussed are both sensitive and controversial. The views presented are not necessarily those of the Editor, or of the Oregon Rehabiliation Research and Training Center. Finally, while the Editor takes responsibility for the accuracy of the statements shown, the editing process may not always reflect the full context in which a statement was made. The reader is reminded that the purpose of the discussions shown in this document is to portray some of the major issues currently existing in the field today, together with the views of a cross section of professionals and consumers regarding those issues. Only as we get a better handle on these issues and problems can we begin to resolve them, and thus move toward the provision of better services to mentally retarded and other developmentally disabled persons.

References

1. Wolfensberger, W. **The principle of normalization in human services.** Toronto: National Institute on Mental Retardation, 1972.

Normalization and Its Impact on Social and Public Policy

Gunnar Dybwad

"Whether it is in Oregon or Massachusetts, Nebraska or Kansas, it is from the persons we are trying to serve that the most important push for change is going to come. By their performance, they will make a shambles out of our classification systems, our assessments, our predictions and our goal settings."

I welcome the opportunity of participating in this Conference on Normalization and Contemporary Practice in Mental Retardation in the hope that there will be a vital exchange of differing positions emanating from the interesting cross-disciplinary group assembled here, and that we will feel free to challenge each other and thus contribute to the clarification of issues by lively debate. Right at the outset, I wish to disassociate myself from what the prospectus for this conference called *the* North American orientation to normalization (author's italics). It reads as follows:

> Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible. *(19, p. 28)*

My objection focuses on three words: normative, establish, maintain. Normative relates to the word norm, which implies a standard of correctness, whether in behavior, writing, dress or other activity. In my book, The Oxford Dictionary, normalization relates to normal, and for me a key point in the normalization principle is that **it is normal to be different**. The people assembled in this room are a pretty normal group. We happen to share a strong interest in the field of disability, in particular the field of mental retardation, but it would not take long to show that we differ widely in how we dress, what, when and how we eat, read, or what we do for leisure.

As far as the other two words "establish" and "maintain" are concerned, they imply in this context an outside initiative and pressure, imply that somebody is being normalized, through norma-

tive action. Therefore, I wish to associate myself with the definition put forth by Bengt Nirje (then in Canada) for the 2nd revised edition of the volume **Changing Patterns in Residential Services for the Mentally Retarded**, published in 1976 by the President's Committee on Mental Retardation:

> The Normalization Principle means *making available* to all mentally retarded people, patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society. (author's italics) *(14, p. 231)*

Surely, inclusion of this definition in one of the key publications of the President's Committee on Mental Retardation should establish it at least as an alternative "North American orientation."

When I first wrote of the normalization principle in 1969 in the first edition of that publication of the President's Committee on Mental Retardation, I linked it with human management programming (7). I have come to recognize that a considerable part of the vehement and persistent opposition to the normalization principle coming from professional colleagues derives from the misunderstanding that the normalization principle implies a normative activity, i.e., someone is being normalized, and I realize that my use of the term human management was unfortunate. It implies a conceptualization of human interaction I can no longer accept. There is an obvious and vital difference between the terms "making available" on the one hand and "establishing and maintaining" on the other, and as I shall indicate later, much of the opposition to the the normalization principle focuses on this factor.

A great deal has been written by those who oppose or question the normalization principle because of its origin in another culture, i.e., the Scandinavian countries, with a cultural orientation which is presumed to be quite different from ours. A review of the historical facts evokes a slightly different interpretation. The normalization principle was first enunciated in Denmark in 1958 by Niels-Erik Bank-Mikkelsen, who had been commissioned to carry through an administrative reform brought about by strong advocacy from the newly organized movement of parents of children with mental handicaps. As Mr. Bank-Mikkelsen has since stated (2), the basis for his policy of normalization was the need for clear and vigorous action to terminate the shocking **de**normalizing conditions he found in the traditional Danish mental retardation residential institutions. In other words, as first conceived, normalization was a specific strategy to counteract the process of denormalization in institutions.

Insufficient attention has been paid by American critics of the normalization principle to a striking parallel in our own country. David Vail, as director of mental health and retardation institutions in Minnesota, published in 1966 a book entitled **Dehumanization and the Institutional Career**, a very detailed critique of the day-to-day practices in the institutions under his care (*18*). Unfortunately, unlike Bank-Mikkelsen, he did not spell out a corresponding corrective program of humanization in the first book and his untimely death deprived us of further writings. But there is a section in his book entitled "The Round of Life" which is strikingly similar to Bengt Nirje's "normal routine of life" and, in a subsequent section, David Vail discusses the need for a normal rhythm of the day, and the need for normal arrangements for eating. In other words, what we can observe here are the reactions of two administrators concerned about similar phenomena inherent in traditional institutional practices, one in Denmark, and the other in the United States.

I was also struck by the comment in the introductory prospectus prepared by the Conference staff, that the normalization principle, "may have lessened both the need and respect for parental opinion and involvement." As far as I have been able to determine, the first printed reference in the United States to the normalization principle in mental retardation appeared in October 1961, in the newsletter of the Saginaw County Association for Retarded Children in Michigan. Betty Hansen, the Association's president, in an editorial entitled "Let Them Be Normal," urged other parents not to deprive their children of the opportunity to attend school like other children (in those days of course, a segregated school, but at least a school). "Sometimes we parents with handicapped children become so absorbed in the differences in them, that we forget that they are as normal as any child in so many ways." Her editorial closes with these words:

> But if we are to do our best as parents of our retarded child, we maybe should be prepared to let him be as normal as he is. The child attending a training center is being given just this opportunity. (*10*)

The National Association for Retarded Children, which a year earlier at its annual convention raised the question, "Are We Retarding the Retarded?" (*5*), reprinted and widely distributed Mrs. Hansen's editorial.

This comment does not seek to imply that the normalization principle has been generally accepted by parents. Here again, it is normal to be different, and we deal (as in the professional field) with a broad spectrum of opinion. Still, it is significant that it was a parent and president of a local parents' association who first enunciated the importance of normal environments and experiences, eight years before Bengt Nirje's (*13*) chapter in **Changing Patterns** was first presented to the professional community.

Inevitably in our discussions here, reference will be made to the application of the normalization principle in the educational field, and the problems created for the nation's school systems with the passage by Congress in 1975 of P.L. 94-142, the Education of All Handicapped Children Act. Therefore, it must be emphasized that already 13 years earlier, Maynard C. Reynolds (*15*) of the University of Minnesota published in the journal **Exceptional Children** an article entitled "A Framework for Considering Some Issues in Special Education," which clearly enunciated the importance of having a broad range of services and of placing children in programs of no more special character than absolutely necessary. He also emphasized that normal home and school life should be preserved (for the child) if at all possible. Dr. Reynolds was also the chairman of a task force of the Council for Exceptional Children which prepared a major policy statement "Basic Commitments to Exceptional Children" adopted by the Council for Exceptional Children at its 1971 Convention, before the first right to education case was settled, and long before Congress passed P.L. 94-142.

Finally, since the conference prospectus made reference to "The North American orientation," it might be useful to recall that at the Canadian Federal-Provincial Conference on Mental Retardation, held in 1964 in Ottawa, Dr. Malcolm Beck, a psychiatrist, stated the following in a discussion on educational services:

> I think we have a problem here of normalization of social experience for the retarded child on the one hand and an accompanying problem which is centered around the present segregation of the retarded. (*3, p. 211*)

His recommendation to the Conference was that educational services for children with mental retardation should be carried out to the maximum extent within the normal stream or, at least within the normal school, and he specified (this was 16 years ago) that this should include those on the "trainable" level.

I have dwelt on these historical references in the hope that this might broaden the base of our discussions and help us pinpoint sources of misunderstandings and misinterpretations, as well as some of the difficulties that are being encountered with regard to normalization efforts in the contemporary practice in mental retardation. Indeed, it would not surprise me if the free interchange of views by as knowledgeable and varied group as has been assembled here would lead us to the conclusion that the broad idea of normalization can and is being expressed by distinctly differing sets of goals, principles, and suggested procedural guidelines.

Normalization and Community Integration

The impact of normalization on the public at large is an area where there seems to be the greatest difference of opinion. Professional literature and conferences like this seem to dwell on the need to educate the public toward better understanding of and tolerance for persons with mental retardation, lest open hostility and contempt bring harm to these defenseless individu-

als. I take a quite contrary view. As one who has been active in this field for 41 years, I have been amazed and gratified how well the general public has responded to the increasing visibility of persons even with substantial degrees of retardation. Considering the vast numbers of such people who are now walking our streets, shopping in supermarkets, who use buses and trolley cars, attend ball games, travel by plane or subway and occupy neighborhood homes, the infrequency of untoward incidents is astonishing. To be sure, there has been much outcry when a group home for retarded persons is to be established in a residential zone, but a nursery school would draw heavy opposition just as well. What **is** significant and to be observed with great frequency, indeed in the vast majority of cases, is that once the home is established, the prior protest notwithstanding, the opposition fades away.

This brings me to a criterion often used to judge the success of normalization programs, which is the extent of integration into the new neighborhood. That is a difficult matter, not just for persons with special needs, but for many of us. I personally do not even recall the names of all our neighbors in the one-family-home neighborhood in our small town where we have lived for 12 years. Our social contacts are elsewhere. Integration into a neighborhood is not easily achieved, indeed. But that certainly does not suggest that we should accept social isolation, and most of the group homes I have visited in various states seem to have established some outreach to neighbors and other meaningful community contacts. To repeat, I have not seen any study of consequence that has accumulated factual data of large scale specific acts of hostility toward retarded persons to back up the oft repeated stories of community rejection. If you have documented quantified data, I should be most interested to review this information.

What **is** of concern to me, however, is the increasingly noticeable rejection by professional workers of normalization activities which enable persons with a substantial degree of mental retardation to live in the community. I have been sufficiently concerned about this development to suggest to some of my colleagues in psychology departments that they should try to stimulate some of their doctoral students to study in-depth the phenomenon of this professional rejection. What is it that causes well trained professional workers of recognized standing to become irritated when they are told of success stories among persons with severe and profound mental retardation?

It is the professional groups, not the folks in the neighborhood, not the man on the street, who will have an influence on public and social policy. Yet, many of them have a minimum of meaningful contact with the persons about whom they are ready to make exclusionary and restrictive decisions based on unsubstantiated assumptions related to irrelevant data. I am keenly aware of the provocative nature of this statement, but it needs to be said and I hope our discussions will touch on this problematic area.

Throne (*17*) is one of a group of psychologists who voices serious questions about the normalization principle. He takes the term "normative" in the definition put forth by Wolfensberger (*19*) and rigidly applying it, arrives at the conclusion that the normalization principle ignores the fact that by definition, the retarded do not develop normally in response to normative procedures. Does he really believe that staff who work with the normalization principle reject a special education program, geared to a young retarded person's needs?

Articles in similar vein have appeared in the journal **Mental Retardation** over the past years with regularity. Aanes and Haagensen (*1*) refer to normalization as a conceptual disaster. They recognize its value as a goal, but, pleading the case of aversive therapy, criticize "unenlightened proponents" of the normalization principle who seem to be opposed to techniques that are non-normal. They derived this information from mailing a questionnaire to 81 teachers and 46 teacher aides.

Charlotte Schwartz (*16*) in an article entitled "Normalization and Idealism" suggests that the entire program of "Normalization" as conceived, has placed an undue burden upon "the retardate's" (sic) psychic structure by exposing him to constant and repeated frustration of enormous magnitude in the everyday world, and that these external pressures are handled primarily by the pervasive use of primitive defense mechanisms. She connects the appearance of normalization (just "a slogan" to her) to the social revolution of the 1960's, emphasizes that man is created

unequal, and points out that no rhetoric can change the immutable laws of nature. She adds: "It is, of course, no surprise if I state categorically that I regard the entire push for normalization as an idealism based upon philosophical ideas which neglect and negate our knowledge of individual and group psychology." (*16, p. 38*) Why do I bother to refer to her views? Because she is a supervisor of social work training at a UAF, a large federally funded University Affiliated Facility specializing in programs preparing persons for professional careers in mental retardation.

This is as good a lead-in as any to some comments about efforts to validate or invalidate normalization programming through research. As a professor in a graduate school, I am dutifully reviewing masses of research projects. They often are very well done from a technological point of view, but many of them are of little consequence, because the research must fit the limited time requirements of the students or of the research grant, rather than vice versa. Rarely are we privileged to see a follow-up such as Edgerton (*9*) presented a decade after his original field study on which he based his book **The Cloak of Competence** (*8*). More such studies are needed to provide us with long range observations of individuals and groups, a valuable source of information.

A particular word needs to be said about mental retardation research based on the concept of deviance. In earlier years, my background in criminology and delinquency suggested my use of this familiar word with reference to persons with mental retardation. But now, a decade later, I have come to question both the relevance and the helpfulness of this psychological frame of reference to persons with mental retardation in general. I keenly resent it if some junior sociologist refers to my friends as deviants just because some junior psychologist, by use of an inappropriate testing procedure, declared them to be mentally retarded.

May I refer to a personal reminiscence. It was in 1968, at an AAMD meeting in California, that I predicted that there would be lawsuits against our state officials if they continued to tolerate the inhuman conditions in our state institutions *(6)*. It was only a few years later that the first of these lawsuits, Wyatt vs. Stickney, took place. In similar fashion may I warn my young and not so young friends in sociology, psychology and social work that if they continue this inappropriate and offensive use of the term "deviant" in referring to persons with mental retardation, they surely will find themselves sooner or later on the receiving end of a libel suit. Laugh at normalization, if you please, but you had better clean up your pseudo-scientific lingo as you speak of people who are no longer your research "subjects," but now lay claim to being your fellow citizens.

One area where normalization has had a real impact, albeit in selected states, is the area of early intervention. Normalization redirected attention to the strength inherent in the family, a strength that could be husbanded if only support services could be made available. To my mind, some of the most exciting innovations have been developed by state departments in conjunction with private agencies. At long range, there is no service of greater significance, no service that will more surely affect the direction of future policy, no service that in turn will more effectively reinforce the normalization principle.

Normalization and Public Policy

Legal scholars, searching for initial recognition of the rights of persons with mental retardation, found the first reference to this in 1960 *(11)*. The rapid development of the state-of-the-art in the legal field and the accompanying impact on the development of public policy can be judged by a review of the volume **The Mentally Retarded Citizen and the Law** *(12)*, based on a conference called by the President's Committee on Mental Retardation in 1973. In this collection of 22 papers, complete with discussion notes, reference is made time and again to normalization as a process useful for the lawyer in documenting the rights and capabilities of persons with mental retardation.

But more dramatic yet, considering the usually

slow response of the judiciary to new situations, has been the acknowledgment by federal judges of normalization as a helpful, viable concept in judicial determination when it comes to the right to education, right to treatment, or right to freedom from harm. References to that effect in judicial orders in the Halderman case in Pennsylvania and the Willowbrook case in New York have been widely cited and thus will have a considerable impact. I am aware that it has been quite fashionable to denigrate the effectiveness of the judicial interventions in the field of mental retardation and to point to "paper victories," to point to inadequate implementation of court orders or consent decrees.

It is strange indeed when state bureaucrats, superintendents and professors who found nothing to criticize at a time when practically right in front of their eyes institutions developed concentration camp methods, who were unmoved by the mayhem, by the death of little children, suddenly speak up and say "this whole normalization business and the related court cases are really for the birds—look how little has been accomplished since the judge put his name under the order." And, having said that, they continue their covert or overt sabotage of any impending change.

Please don't misunderstand me. I would have much preferred that the governor of Pennsylvania had told his superintendent of Public Instruction to get with it, obey the law and provide children with the schooling to which they are entitled. I would have much preferred it if Stonewall Stickney, psychiatrist and mental health director in Alabama, had gotten his act together and submitted to Judge Johnson an honest, viable plan to remedy the criminal neglect of human beings in his institutions. In every one of the lawsuits with which I have been connected, federal judges tried their damndest to avoid a trial, and gave the defendant state officials every opportunity to institute changes.

Federal judges do not have to look for work, they gladly let the executive branch do the governing and the legislative branch the law making. But without the insightful, sensitive intervention of the various federal judges, we would still be in the dark ages. Has normalization had an impact on public and social policy? Thanks to the federal judiciary, that certainly has been the case.

If we use 1950 as a baseline for a pervasive radical reform movement in mental retardation (which does an injustice to some isolated, but significant earlier manifestations), we might say, using some broad and audacious generalizations, that the first of the three decades between 1950 and 1980 saw the emergence of the parents of children with mental retardation as innovators, statesmen and social activists. The second decade added to this a rapidly growing involvement of federal, state and local agencies and a widening cross section of professional organizations. John F. Kennedy created the President's Panel on Mental Retardation and later appointed a Special Assistant on Mental Retardation as a White House staff member. In 1966, Lyndon Johnson established the President's Committee on Mental Retardation. There was the very important nationwide effort for comprehensive state-wide studies of mental retardation which mobilized a lot of agencies previously not involved, through P.L. 88-156. Then came P.L. 88-164 which provided some new funding to establish University Affiliated Facilities and research institutions.

The most significant aspect of the third decade was the emergence of persons with mental retardation themselves, as members of our society, as human beings with a claim to personal integrity and as citizens endowed with legal rights. The beginning of this remarkable development is documented in the proceedings of the 1960 Golden Anniversary White House Conference on Children and Youth *(4)*. Increasingly, normalization efforts and programs have aided persons with mental retardation in their quest for an appropriate existence among us. Indeed, by this time, in many ways, we have a reciprocal relationship in that the steadily increasing number of persons with mental retardation who function in the community as the result of normalization efforts, in turn, by their very presence and the quality of their adjustment, are providing impressive support for further normalization programs.

It is undoubtedly due to the new awareness of normalization that we now have persons with mental retardation who serve as members of state councils and committees. In my own state

of Massachusetts, we just had the third Conference of Persons with Mental Retardation, managed by themselves to a considerable extent. At the time of the previous conference, they had as keynote speaker a young man from Connecticut, who, rebuffed by some community establishments, went to his legislator with his complaint, was invited to meet with a legislative committee, convinced them that his cause was worthy of action and two years later Connecticut had a new antidiscrimination statute. After he spoke to his Massachusetts friends, they in turn got busy, sent delegations to the State House and successfully lobbied for similar legislation, which was recently signed by the Governor. A major feature of the third State Conference was a workshop which provided training in independent living; the young woman who made this slide presentation in a very accomplished fashion, some years earlier herself had been in a mental retardation institution and, no doubt, had not been considered "educable."

There are increasing instances when newspaper stories report in responsible and respectful ways about events involving mental retardation. Perhaps some of you will understand how touched I was when I read recently in the Boston Globe a fairly lengthy obituary about a young woman who had died as a result of injuries suffered in an automobile accident a year earlier. There was a reference to the fact that she had graduated from a school I recognized as one of the old special schools, and there was also reference to her having worked in a place I knew as a sheltered workshop. When a young woman with Down's Syndrome can die in dignity and have an obituary which extolled her kindness and her popularity, I am bold enough to say that normalization has brought us a long way.

Whether it is in Oregon or Massachusetts, Nebraska or Kansas, it is from the persons we are trying to serve that the most important push for change is going to come. By their performance, they will make a shambles out of our classification systems, our assessments, our predictions and our goal settings.

References

1. Aanes, D., & Haagensen, L. Normalization: Attention to a conceptual disaster. **Mental Retardation,** 1978, **16**(1), 55-56.
2. Bank-Mikkelsen, N. E. Patterns which are changing: Denmark. In R. Kugel & A. Shearer (Eds.), **Changing patterns in residential services for the mentally retarded** (Rev. ed.). Washington, D.C.: President's Committee on Mental Retardation, 1976.
3. Beck, M. Discussions on educational aspects. **Mental retardation in Canada.** Department of National Health and Welfare, 1965.
4. Dybwad, G. Trends and issues in mental retardation. **Children and youth in the 1960's.** Washington, D.C.: Golden Anniversary White House Conference on Children and Youth, 1960.
5. Dybwad, G. Are we retarding the retarded? **Challenges in mental retardation.** New York: Columbia University Press, 1964.
6. Dybwad, G. **The undeveloped resource at the edge of change.** Paper presented at the Fall Conference on Mental Retardation cosponsored by the American Association on Mental Deficiency and the California Council for Retarded Children, San Francisco, November 16, 1968.
7. Dybwad, G. Action implications, U.S.A. today. In R. Kugel & W. Wolfensberger (Eds.), **Changing patterns in residential services for the mentally retarded.** Washington, D.C.: President's Committee on Mental Retardation, 1969.
8. Edgerton, R. B. **The cloak of competence: Stigma in the lives of the mentally retarded.** Berkeley and Los Angeles: University of California Press, 1967.
9. Edgerton, R. B., & Bercovici, S. M. The cloak of competence: Years later. **American Journal on Mental Deficiency,** 1976, **80**, 485-497.
10. Hansen, B. Let them be normal. **News and Notes.** October 1961, Saginaw County Association for Retarded Children, Michigan.

11. Kay, H. H., Farnham, L. J., Karren, B. D., Knackel, J., & Diamond, P. M. Legal planning for the mentally retarded: The California experience. **California Law Review,** 1972, **60**(2), 438-529.
12. Kindred, M., Cohen, J., Penrod, D., & Shafner, T. (Eds.), **The mentally retarded citizen and the law.** New York: Free Press, 1976.
13. Nirje, B. The normalization principle. In R. Kugel & W. Wolfensberger (Eds.), **Changing patterns in residential services for the mentally retarded.** Washington, D.C.: President's Committee on Mental Retardation, 1969.
14. Nirje, B. The normalization principle. In R. Kugel & A. Shearer (Eds.), **Changing patterns in residential services for the mentally retarded** (Rev. ed.). Washington, D.C.: President's Committee on Mental Retardation, 1976.
15. Reynolds, M. C. A framework for considering some issues in special education. **Exceptional Children,** 1962, **28**, 367-370.
16. Schwartz, C. Normalization and idealism. **Mental Retardation,** 1977, **15**(6), 38-39.
17. Throne, J. M. Normalization through the normalization principle: Right ends, wrong means. **Mental Retardation,** 1975, **18**(5), 23-25.
18. Vail, D. J. **Dehumanization and the institutional career.** Springfield, Ill.: Charles C Thomas, 1966.
19. Wolfensberger, W. **The principle of normalization in human services.** Toronto:National Institute on Mental Retardation, 1972.

Normalization and the Consumer

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"Was there a thought when normalization got going here in the states that maybe the consumer would only be a receiver of the process? Is it that no one ever expected that the consumer would really be able to understand or give input or make suggestions? Was the problem that no one took the time to talk to the consumer, or maybe it was that no one had the time, or maybe it was just an oversight?"

People First International is a self-help group of consumers which originated in Oregon in 1974. We currently have 22 chapters in Oregon and have supplied consultation and assistance to over 40 states regarding the process and procedures for organizing and implementing consumer groups. At our last national conference, we had over 1,000 consumers who came to speak for themselves and have support from their friends.

From the very beginning, the People First process has been one in which people with handicaps and helpers together make the movement go. This process enables persons once institutionalized or labeled retarded to gain a positive self-image. The role of helpers is to realize where people are and to help them plug in where they may have potential strengths and skills.

The three of us come from a tradition where the labeling of people is very sensitive. So in our presentation, you will not hear the words "mental retardation." You will hear consumer. You will hear people. You will hear names, but you will not hear labels. Maybe one of the challenges that we from People First can offer to this gathering is that we all be sensitive to the labels that are used at this meeting. Also, in putting our presentation together for today, we recorded conversations about normalization with other consumers back home. We will use these conversations in our presentation to help make our points.

Normalization: Has the Consumer Heard the Word?

The normalization process to date has not involved the consumer. They know something is going on, however, and that it affects their lives. Since they haven't really been talked to about this concept or value, they have little to say about it. It seems to us that the conversation to date about normalization has come from parents, teachers, social workers, administrators and researchers. Even when it comes to talking about what is normal and who is normal, the consumers have a difficult time.

Recorded Conversation

Helper 1: "Who knows about normalization? . . . What is normalization?"

Helper 2: "Has anyone ever heard that word?"

All Consumers: "No . . . no . . . no."

Helper 1: "Let's ask it again . . . just in case you might remember it all of a sudden, ok? What is normalization? Does it ring a bell with anyone?"

Consumer: "No."

Helper 2: "Ok. Let me try something. Let's see who . . . Janet, I know you have gone to some different schools . . . and Donna . . . I bet you've gone to some places. What if somebody asks, what does normal mean? Does anyone know that? What is normal? Anyone ever hear normal?"

All consumers: "No . . . no."

Helper 1: "Ever hear that word?"

Helper 2: "Never?"

Helper 1: "Don't you know what that word might mean?"

All Consumers: "No . . ."

Helper 2: "What do you do if you're normal? What kind of things do you do every day if you're normal?"

Consumer: "Work."

Helper 2: "Work!"

All Consumers: "Go to school . . .go to school."

Helper 2: "Go to school. Alright. What else do you do if you're normal?"

Consumer: "Play . . . ?"

Helper 2: "You play."

Consumer: "Chase boys . . ."

All Consumers: Laughter

Helper 1: "Let me ask this question. Are people at the institution normal?"

All consumers: "No."

Helper 2: "No? Kathy, why aren't they normal?"

Consumer: "I don't know, but some of them are."

Helper 2: "Some of them are. Are there some of them that disturb you?"

Consumer: "I used to go visit Sydney, and some of them used to tell me to go away. And then, they told me I couldn't go visit him anymore because . . .that's where children go."

Helper 2: "Were you normal, Kathy and Janet and all of you, were you normal when you were at the institution?"

Consumer: "We were handicapped."

Helper 2: "You were handicapped?"

Consumer: "Yes."

Helper 2: "Who's handicapped?"

Consumer: "People that live there."

Helper 2: "At the institution . . . you were handicapped. What about the women that live at the group home? Are they handicapped?"

Consumer: "No. I don't know."

Helper 2: "Are they? Take a look around. Are they handicapped?"

Helper 1: "What do you think, Linda?"

Consumer: "No."

Was there a thought when normalization got going here in the states that maybe the consumer would only be a receiver of the process? Is it that no one ever expected that the consumer would really be able to understand or give input or make suggestions? Was the problem that no one took the time to talk to the consumer, or maybe it was that no one had the time, or maybe it was just an oversight?

We have consumers who have never been and are still not a part of the process going on around them. They have not been prepared for the changes that are happening to them. The consumers are the receivers of a process, but they are often failures in coping with it.

Normalization: Has the Community Heard the Word?

When normalization began in the United States, the consumers were seen as strange looking people. They acted kind of funny and different from the rest of society. They were set apart. They didn't fit. They were seen as a deviant group and became a labeled group. They were labeled as morons, idiots, imbeciles. The consumers even called themselves names. If you have ever been in an institution, you will often hear the residents there call each other low grades. There was no community role for the consumer unless being an oddball or weirdo was a role.

The community often relegated the consumer to institutions. In the institutions they were seen as a limited and hopeless group of people who would never be able to care for their own needs. They were seen as easily led, easily managed and obedient. Institutions liked that kind of behavior because it kept the institution in order.

We taught consumers that in order to survive, they needed to be totally dependent on others. Consumers learned to ask their aides and to ask their parents for anything they wanted, but the last people they learned to ask were each other. They certainly didn't think to ask themselves. All of their needs were met by authority-type people. The message of dependence and hopelessness rang loud and clear in the ears of the consumers when normalization practices began in the United States.

Recorded Conversation

Helper 1: "How many people lived at the institution? Raise your hand if you ever lived in an institution."

Helper 2: "I think everybody here has."

Helper 1: "Let me ask this question now. When you lived at the institution, who did you go to for help?"

Consumer: "Aide."

Consumer: "I'd go to my aide."

Consumer: "Go to your aide."

Helper 1: "Everybody agree with that? Did you all go to your aide for help? Is that where you went, Cindy?"

Consumer: "Yes, I did."

Helper 2: "How about you, Linda? Did you you go to your aide for help? I mean when you wanted something, who did you go talk to?"

Consumer: "To my aide . . . I miss my aide."

Helper 2: "You miss your aide, huh? How come you liked that aide?"

Consumer: "I liked it because he'd give me my T.V. and licorice."

Helper 2: "How about when you moved to the group home? Who do you get your help from now?"

All Consumers: "Aides . . . everybody . . . the police."

Helper 2: "Who do you get help from? Who do you ask for help now?"

Consumer: "The police."

All Consumers: "No . . .no."

Helper 1: "Now, Mike is saying if you need help you go to the police."

Consumer: "Yeah."

Helper 2: ". . . say something, Fred."

Consumer: "If you're in a group home and you have a problem, you go to the staff."

Helper 2: "Well, that's just like the aides, isn't it?"

Consumer: "Yeah."

Helper 2: "Well, before we had the aides . . . now we got the staff."

All Consumers: Laughter.

Helper 1: "But I don't understand . . . then explain this to me. If you need the aides and you need the staff, why do you say that you need each other? You don't need each other at all."

Consumer: "No . . . We got a home now."

Helper 1: "Do you need each other at all?"

Consumer: "No."

Consumer: "Yeah. . . . You don't use the staff if you live in a . . . apartment . . . like . . . a . . . Pam . . . Mike and you. You people live in a city home. You guys live with each other, right? And help each other without going through the aides . . . I know . . . I know for a fact you don't go to the aides. If it is necessary, yes, other than that, you can do what you want as long as it isn't anything wrong."

Normalization has not encouraged or given consumers access to peer support systems, peer relationships, peer decision making, peer culture or peer history. The roles of the institution aides have been replaced by the roles of the group home staff. So dependence on others is still essential to the survival of the consumer.

We have a society who sees consumers moving from institutions into their communities. Yet, they continue to label and avoid them. They set them apart. It's easier to set this group of people apart than to have to deal with them, because once you label a group, you never really have to talk to them. They don't become real in your life as a community member.

The fact that a process or a plan of some sort is happening by educators, by philosophers, by social workers has not been translated to your average community member. They don't understand why this group of people used to be out at the institution and are now trying to get group homes in their neighborhoods.

Can We Be Together?

Normalization has not adequately met the social needs of the consumer. Consumers find special and important meaning in their relationships with each other. They need each other. Consumers don't like to be lonely or isolated in the institution or the community.

One of the best ways consumers have found to talk to each other is in groups. Groups all over Oregon are getting together to talk, share feelings and think. They are learning how to speak about what is on their minds. When consumers left the institution and came to the community, they didn't know how to talk to each other. They knew how to go to authority figures for their strokes, but they did not go to peer groups for support.

We set in motion what we call our support groups which eventually became the cornerstone of the People First movement. When the consumers come together, it's their time, their agendas, and their speed. They're learning how to make decisions, and how to feel good about themselves. They're learning how to accept themselves as people first and not handicapped first. We found that the group process really stimulated a peer support system. We think that the one-on-one approach in trying to get consumers into the main flow of society has been shortsighted.

Recorded Conversation

Helper 2: "Do you all need each other?"

Consumer: "Yes."

Helper 1: "Why?"

Consumer: "Why?"

Consumer: "We do need each other."

Helper 1: "Why do we need each other. Why, Pam? Why do you think that we need each other? You're saying we need each other."

Consumer: "Because we want to learn to help each other."

Helper 1: "Ok."

Consumer: "Being friends and helping each other is really good to do because I feel that we have some . . . that we all have handicaps one way or the other . . . and this is what People First is all about. It is to help us. What I'm saying is that I like to help people."

Helper 2: "Do you think that with People First and the groups that go on, that people share with each other?"

Consumer: "To some extent, yes, because . . . when you're around one another a lot, you feel sort of like in a group . . . nice. We all feel warmth."

Consumer: "We knew each other before."

Helper 1: "Where do you know each other from?"

Consumer: "Most of us have known each other from being in the institution. Most of us have lived there . . . for some period of time. We have gotten to know each other quite well. If we did not know each other, we'd be like strangers."

All Consumers: "Right . . .yeah."

Consumer: "Let me . . . going from the institution to the community . . . then from the community to being an individual in an apartment is a stranger like step. Everything is strange."

Consumer: "What group do we belong to, people?"

All Consumers: "People First."

Consumer: "We all work together in each county . . . you know, in People First. And it is big . . . and we got the power over you guys."

Consumers need a group identity. They need a culture, a history and their own heroes. They need each other so that they're able to develop what the rest of society has. Think of yourselves. You all come from someplace. You all belong to groups. Groups give a special meaning and identity. Without developing a history, the consumer will have no identity. Without a background, a group identity and a culture, it is almost impossible for the consumer to have input about where they are going.

Summary

Normalization will have to change or it won't be meaningful to the people it is supposed to affect. We can talk pretty clear, but some of our friends cannot. They use sign boards, sign language, and their bodies. Many of our friends have a difficult time getting in front of a group and talking. They want us to communicate to you what needs to happen regarding normalization.

First of all, we want you to understand that we are people who have something to offer others, and that we have needs which have to be met. We want to have a say in our lives and our friends want a say in theirs. We want to be part of plans being made about us. We want to talk to you professionals, but you will need to slow down and use simpler words. We want to get together with our friends and do more than bowl, dance, run a race or watch T.V. We want to talk about our lives and what we need. We want to feel close to each other. We want to make decisions that affect our lives. When rules are made and programs run on us, we want input.

We used to ask for permission from our aides, our group home staff, or our parents, whenever we wanted something. We and our friends in Oregon and in other states forgot to ask permission to meet, and we have been meeting together in groups from 10 to 1,000 for the past six years. We are helping each other to make it in the community in spite of normalization. And by the way, is it okay if we keep meeting?

Participant Discussion

MR. DYBWAD: I'd like to bring a specific point from this morning's discussion to the basic premise of this conference, and that's the definition of normalization. I hope you all realize that what the consumers have presented here is an absolute contradiction to Wolfensberger's theory. It's about time that we act on this, because as you know, Wolfensberger is a dear friend of mine and has waxed eloquently that we must never allow deviants together. Bull! You heard this morning that these people want to be together, and all this normative stuff has to be turned around.

If you keep on with Wolfensberger's theory and at the same time try to support these people, you are doing the impossible. So it isn't just that we haven't gone far enough. We have to backtrack and recognize that in 1968, in 1972, we made some basic mistakes. You see, I no longer believe in human management. I believe in management of the electric company and so on, but not of people.

This one point, that they want to be together, that they find strength from each other, is similar to what Edgerton found in his follow-up that I mentioned yesterday. He found that mentally retarded people who were getting together with each other gained strength, rather than being dependent on some benevolent outsiders.

So the point which is coming out here is that we need a reorganization of our original conceptual thinking on which a lot of this so-called research has been based. I really want you to recognize that we are shaking the boat, and if you don't take care of this, you will fall out of the boat.

MR. ROOS: I'd like our deliberations to reflect some of the controversial issues which certainly exist in the field. Gunnar has, I think, very accurately identified some of these. Since Dr. Wolfensberger is not here, I'd like to try and respond to Gunnar's comments as I think Wolf might, although I want to be clear that I happen to be in Gunnar's corner in this particular conflict. I think he's absolutely right.

I think that Wolf would argue, however, that the tendency of handicapped people to coalesce into homogeneous groups results from the fact that they are still rejected, labeled, and as a result, isolated from the rest of society, and that by continuing to aggregate in small groups, this model of islands of deviancy is perpetuated. His model, I think, would argue for a dis-

persal of such individuals. He would argue that if these individuals come in close and intimate contact with non-handicapped people, they can then begin to form bonds that are based not on a communality of a particular handicap, but on other communalities of interests. I want to make clear that I do not happen to believe in the validity of this, but I think that that would be the basic argument that Wolf would present and I think that at least we should be cognizant that there is some rationale for that posture.

MS. KAPLAN: Why is that different from a woman's perspective now? Why is that different from what I heard when I was growing up, about women meeting together and the women's movement? Women don't need to meet together. Let's just keep them where they are. Meeting together creates power, you unite, you become a part of what's happening in society and make demands. I heard what you were saying as very similar to how I heard a lot of that translated.

MR. ROOS: I may be inaccurate in guesstimating how Wolf would respond, but I think Wolf would argue that women are not a minority, that there are almost as many women in the world as there are people. So when women gather, they are not perceived as an external group, as a deviant group, and they are not isolated and segregated. Indeed, there are compelling psychophysiological forces at work within our society which attract the remainder of society, namely men, to women.

With handicapped populations, I think he would argue we are dealing with very small minorities and that through their congregations they are further isolated and segregated, and thus decrease the possibility of developing meaningful bonds with non-handicapped people. I believe that would be Wolfensberger's line of argument.

MR. SOENNEKER: If you take the Wolfensberger definition of normalization, it's characterized in terms of certain continuums, such as the dependency-independency continuum or the segregation-integration continuum. I think that the continuum itself may, in fact, be a false continuum. The goal really is not independence, but it is interdependence. The goal, as Phil said, is not integration, but rather communalism.

If you look at comparable kinds of "deviant" groups, the struggle which the dominant society has tried to impose is really the process of making them like the dominant group. I think that as groups have gotten organized, they didn't want integration, salt and pepper integration. What they wanted was equality and communalism within a society, and I think we are seeing the same kind of a transition taking place here with reference to mentally retarded or handicapped people. What they need is a form of interdependence and a sense of communalism within society. That's really what I am hearing the consumers saying.

MS. BROWN: In preparing my presentation for tomorrow, I read and reread quite a few materials, and one of the things that really struck me was the warning to not make integration the goal of normalization, that normalization was a means, a method, one of perhaps many.

The provision of opportunity for people to make decisions about their own lives and to have exposure to new experiences are the goals of normalization. I think we are getting hung up with people being so into the process, into the method, that integration which has been stressed as one of the procedures, has become the goal. We forget what it was that those folks way back there were talking about in the first place.

The analogy that keeps coming to my mind is in terms of the Black movement. People got so hung up with busing and arguments about whether that was good or not, that a lot of people lost sight of what that one method was supposed to do.

MR. HARPER: A profound thing that came out of this morning's session, was that when the consumers were asked if they knew what normalization was, they didn't have a good response for that. Further, they said if you are going to be having a party for us, it would be nice to invite us to that party. I felt that was a very profound statement.

When I went outside and got a little air and thought about that, I realized that if we went downtown here and went into a cafe and asked

people what they thought normalization was, they probably would have the same response. They wouldn't know what we were talking about either, and I don't know whether or not they would want to get involved with it.

The point I am trying to make to you here is that I think we would be fools if we thought normalization was something that was just accepted by everyone, because it certainly is not. We have encapsulated this whole business of MR/DD, all the entire tapestry, into one word, normalization, which the people that we are supposed to be serving don't understand. Is normalization everything in the world encapsulated in one word? Does this august group really believe that normalization encapsulates what the entire MR/DD movement is all about?

MR. ROOS: No, I don't think so.

MR. DYBWAD If you would ask Bank-Mikkelsen, who first talked about normalization, he would say, "For heaven's sake, no. I hope the term will disappear totally." To him, normalization was a concept, anti-denormalization, and he hoped and prayed that denormalized conditions would disappear so that people would no longer have to talk about normalization.

I think David Vail hoped that dehumanization would disappear so he wouldn't have to preach humanization. In other words, originally it was not meant to be a life's philosophy. It has been built up to this in the eyes of some people, but I completely agree with you that we can't encapsulate the entire MR/DD movement into this one word.

Hence, we deeply believe that the people who used to live in an institution are human beings like us. If we try to encapsulate their lives in one word, that means our lives can be encapsulated in one word. It can't be. Impossible. So that is a wrong idea, and I think the quicker we realize that, the better it is.

MS. SCHAAF: Whenever those of us who were residents in the institution talked about the outsiders, or the people in the community, we spoke of them as normal persons. At that time, we did not feel that we were normal. We didn't know exactly how to describe or put a name on ourselves, because we felt that people out in the community were more normal than those of us in the institution. That was the way we looked at it. That may have been a wrong way. That may have been the right way. I do not know. But as you say, human beings are human beings, and there are all different kinds of stages of normalization. Everybody has different ideas, different concepts.

MR. COOKE: If you think of being a normal person as someone who is behaving like other people, which is what Gunnar was attacking last night, you have one picture of normalization. If you think of a human being as someone who makes choices (the choices may be the same as yours or they may be grossly different) then normalization has a very different connotation. They may make mistakes in their choosing or they may be very wise, but nevertheless, they have a choice. Now the problem is, how do you help people who haven't been given many choices or many opportunities to choose in the past? How do you give them the tools, so to speak, to make choosing easier? It seems to me that's what the helpers of People First are trying to do.

MR. SOENNEKER: It seems to me that we have the perfect capacity to design a machine for anything, and what we have designed is the perfect normalizing machine. It permeates the whole system. It's an integrated kind of thing. Somewhere along the way, however, we lost track of the point that Bob Cooke was making in terms of choices.

The fundamental principles of our society embraced in the Constitution and Declaration of Independence, are the basic rights of life, liberty, and the pursuit of happiness. Now, if you think about that a minute, there is a conflict in this, which is what we are confronting here. Society has a dual moral duty, if you will, on the one hand to respect the right of people to do whatever they want, and on the other hand to take care of people who can't act in their own best interest. For example, we will not allow people to starve to death who are profoundly retarded, because we recognize that we have a duty to help them. On the other

hand, you will all allow me to smoke two packs of cigarettes a day, drive down the street without seat belts, or ride a motorcycle without a crash helmet, because you (society) make the judgement that your duty to respect my liberty outweighs your duty to protect my life.

When you deal with mentally retarded persons with diminished capacity, you get very much into that conflict. Now, I'm not sure exactly how normalization fits into this, except that we have designed a machine (normalization) that allegedly is trying to create an environment of respecting retarded people, but, in fact, the technology we have designed to implement it is doing precisely the opposite. It is completely mechanising and controlling the environment to the point where the consumer really has no choices.

MR. MAUTHE: The consumer wants input in terms of what is happening in the home they are residing in. Did you receive a lot of resistance from the group home staff, either because of their attitudes or because of rules and regulations imposed on the home?

MS. SCHAAF: In some cases, yes, but it depends on the person in the group home, too. You don't really have to go and ask permission to do this or ask permission to do that. If you have a job, make sure you go to it, it's your responsibility. Most of us have our own responsibilities that we can do without asking for permission. But there again, if we want to go out to a movie or go shopping, we have to let the group home provider know where we are going, because they have some authority over us. Where would they find us if some emergency arose, like, say the group home got on fire and we weren't there? They would have to know where we were at that time or why we weren't there.

MR. HEATH: I think that some of the resistance has to do with control, control of the people that live in the facility. If they go out and see other facilities and listen to how other people live their lives, the consumer may not want to stay in the facility s/he is presently in. There is some of that fear in residential facilities.

Another form of resistance has to do with simple things like money. Facilities generally manage the personal money of the resident or consumer that lives in that facility. And so there is no encouragement, there is no breaking down some of those barriers and making it a little easier for the people.

MS. KAPLAN: One of the things we find with group homes is that they're most responsive to what the money givers say; the state, who gives them their licenses, and the county, who funds their program positions. One of the things I would have loved to have had in our presentation would have been the service providers themselves talk about normalization. I assume that some of the basic aspects have never been translated to them. For instance, if you run a group home, let's talk about what is a group. How does a group work? In the institution, people are in cottages and no one deals with those people as a group. In group homes, it's no different. None of the money givers are saying that normalization includes the group process and therefore encourages working with the people in groups. In fact, it's the opposite.

Programming money in Oregon, and I don't know how many other states in which this is true, is given if you want a program for zipping your pants or brushing your teeth. But, the **group process** is not considered a program, and the home is not supported for funding group programs.

MR. DYBWAD: I have one question I'd like to ask the panel. At this point, I am so upset about normative. Normative relates to norms, regulations and so on. I find myself very disturbed at the avalanche of rules and regulations that emanate from the Title 19 people from the Department of Mental Health and so on. Everybody is regulating at the moment (in the

name of normalization) the lives of people who live in the community. For example, we are safeguarding confidentiality and privacy to the extent that it really attacks the basic rights of these people. There is not a photographer allowed within 15 feet of any person who used to be in an institution. It seems to me, and I speak specifically of Massachusetts, but I have enough information about other states, that we are using this normative idea in ways that actually are rather detrimental and restrictive to the lives of the people.

How is Oregon? Have your people been concerned about the regulatory avalanche that comes from the state agencies as to what group homes need to do, how they should be constructed, what a group home needs to know, needs to do, needs to file records about and so on, or have you been blessed?

MS. KAPLAN: No, we haven't been blessed.

MR. DYBWAD: Privacy and confidentiality, have you had problems?

MS. KAPLAN: Terrible.

MR. HEATH: The people can't even find out where others live.

MR. DYBWAD: Precisely. A Jewish agency in Springfield, Massachusetts, heard that Belchertown Institute was discharging some people. They felt that, my God, they really ought to do something. They wrote to the regional office and asked for information. They were told that the information was confidential. So here was a community group of citizens who wanted to do something, and confidential of course, was stupid.

MS. KAPLAN: Dennis and I have been through this for eight years now, and everyone around us talks about quality, and not quantity. You know, we have all heard that. I am really becoming more and more convinced that the quality comes in voluminous paperwork. Oregon's got a great program. They have programmers, programming everybody 19 hours a day.

MR. HEATH: Everybody has their own clipboard in the bathroom, the living room, and in the kitchen.

MS. KAPLAN Its become very much like the institutions which have obedient, manageable people for the benefit of the institution. I am beginning to believe strongly in the consumer reaction that all this programming is not to their benefit, at least to some degree. Now, we have got to find a common meeting ground.

MS. ROBINSON: I have this real fear as I am sitting here, because in Wyoming we started the People First program and the community program. First we put them on a bus, and away they went to work, and then back from work. Then they sat in the group home. Then we put them on the bus again and we took them to the People First meeting, and then they went back to the group home again. We ought to look at the consumer movement. I have a real fear that everybody will jump on the bandwagon and immediately **program** in a consumer movement, and we'll see it all over the country.

Now, your consumer organization hasn't worked that way because your helpers are very dedicated and willing to stand back, but I did see it happen a different way in Wyoming. I have heard that what happened in Wyoming also happened in Montana and some other places.

MS. KAPLAN: The role of the helper is critical, is what you are saying.

MS. ROBINSON: Okay. That's one thing. The other thing is that we may be critical of the regulations, but we are the very people that asked for them. In Wyoming we may be farther behind than other programs, but the consumer movement is the strongest right now, and the consumer representatives are the people that are asking for lots more regulations and standards.

It is the standards that are horrible, I agree, and they are a problem. But, I think we have to look at ourselves, because we are the ones that created them. You know, most agencies don't just pull standards out of the air. They wait until somebody starts complaining, or there is a lawsuit or something.

MR. HEATH: In that whole process in Oregon, the cart was before the horse. The

people were in the community before the programs were there. Then when everybody started yelling because all these people were sitting around in boarding room facilities and had endless time on their hands, the standards came as a reaction to the looseness.

MS. KAPLAN: The People First consumers in Oregon meet naturally at work, and meet naturally at home. We don't bus people anywhere. We have natural gatherings. In fact, several of the activity centers and workshops have their own People First chapters right there as part of their day. The people in group homes meet together. They are within walking distance. They do it at night. Some people do it both day and night. I mean, it's in natural gathering places. It is not separate and apart from their life activities.

MS. ROBINSON: The very point is that if we had a chapter in the work activity center, everybody in the work activity center, whether they like to meet in groups or not (and I am not a group person), would have to sit in on the People First meeting because it is in the daily schedule, the work activity.

MR. HEATH: I appreciate what you are saying, but the reality is that people that we have known, both people that have been at the institution and people that have not, need a basic process where they can make use of each other to get their basic personal needs met. In the nursing homes where I am a consultant, I'll do everything I can to get a person out of his/her room and down to the activity center room, to bring some orange juice and sit down and start talking to another person. I'll manipulate them. I'll seduce them. I'll do that because I know that a group process will be helpful to them. They will always say, "No, I don't want to go to a group, I don't want to be a part of that." I have seen similarities with senior citizens and the consumers that I have worked with, that the basic reaction to anything is no.

MS. KAPLAN: Part of the problem the consumers are having is translating their own movement. For example, when registration for our annual convention happens, we get responses from group homes that none of their people want to go. Then Valarie will go out and ask how come no one wants to go and the people will say that they weren't asked.

MR. MAUTHE: I know of nothing in Title 19 regulations or in Wisconsin's community residential facilities' regulations that would prevent any individual living in a community residential program from exercising his or her right to advocate for themselves. I'd like to go on record, too, incidentally, in saying that I think People First is one of the best things that has happened in recent years. I think one thing that has to be recognized though, is that an agency must be held accountable for the expenditures of tax dollars. If an agency isn't programmatically and physically accountable, then it is subject to public exposure, or at least open to investigation.

Group homes are subject, then, to liability and are heavily influenced, for example, by the insurance industry. There are many, many influences. I think there is a lot that can be accomplished through People First and other self-advocates. That's where the major impact is going to come in terms of changing regulatons. But I think the provider of service is still going to have to be accountable programmatically and physically.

MS. KAPLAN: What you are saying makes sense, because I understand the talk about documents et cetera. But I have watched the evaluation processes in Oregon with much amazement, because there are tremendous rules and regulations and there are teams that go in and evaluate and look at records and charts. When do they talk to the consumer? What does the consumer think about what is happening?

MS. SCHAAF: When I was in the institution, back through the years of 1956 through 1972, I was not programmed. It is very, very funny for me to see some of the programs going on now in the institution. Some of the things that I could always do is what some of these people are now being programmed to do. When I left there, I went to school. I had a job in one of the cottages, and then I came home. Then I had some time of my own. I wasn't really programmed.

When I left the institution in 1972, I went into a group home. I was not programmed. I had a lot of time, and I didn't really know how to deal with time. Whenever I did have time, I didn't want to do the same thing that others were doing. I felt like I wanted to be myself. This is generally what a lot of them want to do, but they also want to learn how to deal with their time in their own way. A lot of people are not given that chance.

Nowadays they are programmed from morning to night, and then the next day it starts all over again. It gets tiresome, I believe, to these people, because they do not have their own willpower to express themselves during the day. It's just overwhelming to see how tired some of these people are, some of them that are working out in the community on their job to earn money for spending, or to earn money to pay for their own group home. A lot of these people would like, more or less, a program to deal with their free time, how to do some of these things wisely. If you don't help them with this, you are throwing them back into the days of idiotness, of being dependent on someone else. If you don't want this to happen, make them as independent as possible.

I think we need to change a lot of the concepts in institutions and in the community, to let these people do their own planning and make their own decisions. Let the peers, the group home providers, and the staff sit back and watch them. They need a lot of encouragement to even give it a try.

Normalization and Society

Philip Roos

"Our society offers some subcultures which deviate significantly from the dominant normative patterns, yet they are available to most nonhandicapped people. For example, communes are an available option to most people, although they are not exactly the normative pattern in our society. The same is true of multi-family aggregates or homosexual communities. Should such options be available to mentally retarded people as they are to nonhandicapped populations, even if they are not normative?"

The only constant in the universe is change. The universe is in constant flux, and this certainly applies to society, which is rapidly changing all about us. Thus, to talk meaningfully about normalization and society, it is important to remind ourselves that society is not a static phenomenon, but is highly fluid and dynamic.

Some futurists propose, for example, that within the next 20 years society will shift from an economy of scarcity to an economy of abundance. The Protestant work ethic will be replaced by a psychological model of work. There will be a heightened value of the individual and a blossoming of humanistic values. The concept of total employment will replace the current emphasis on full employment, with the goal of work being that of maximizing human potentials.

Other futurists predict a shift from competitiveness to cooperation, resulting in limited individual objectives, humanistic goals and greater emphasis on self-fulfillment. Still others emphasize new approaches to satisfying basic human needs. They feel, for example, that society is shifting toward a multiplicity of heterogeneous minority subcultures, so that speaking of a normative society or a "normative pattern of life" may become less and less meaningful. Instead, society will provide an increasing range for individual choices of life patterns, greater mobility, more frequent career recycling and a wider variety of personal roles and lifestyles.

Some social scientists anticipate more alternatives to the nuclear family, such as communal living arrangements and symbiotic relationships between people with different handicaps who are able to complement each other. Biological parents may increasingly be replaced by professional parents, i.e., individuals who will be trained in parenting and who will be paid for raising children.

Society may also shift toward a greater emphasis on information, so the possession of information may become more important than economic growth. Communications systems may largely replace transportation systems, leading to a decentralization of work forces and a return to

the local neighborhood as the focus for work and social life.

Shifts in ethics and values are already apparent. Thus, some fundamental concepts are being reevaluated, concepts such as independence, self-sufficiency, sexual roles, and the importance of achievement and status. Indeed, the meaning and the definition of life itself are being reassessed. These are the kinds of dramatic changes which can be anticipated within our society. They will have obvious implications for the concept of normalization.

Confusion Regarding Normalization

Normalization has become the subject of a great deal of fuzzy thinking, so that it is now difficult to clearly identify the issues relating to this concept. One source of confusion is that normalization has been given at least two major interpretations. Each of these interpretations has different implications and leads to different consequences. Failure to differentiate between these two definitions has contributed to considerable confusion about normalization.

The first interpretation of normalization is as a means, i.e., as an approach to mentally retarded people. This is the definition which was originally developed by Bengt Nirje in 1969:

> The Normalization Principle means making available to all mentally retarded people, patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society. (*17, p. 181*)

Based on this definition, we do not normalize people, we normalize environments. This definition also implies that the process of normalization is inherently desirable for mentally retarded people as well as for society in general. Bengt Nirje, in 1977 stated, "It (normalization) gives society a chance to know and respect mentally retarded persons in everyday life and to diminish the fears and myths that once caused society to segregate them" (*8, p. 5*).

The second interpretation of normalization refers to a process (i.e., to a means) as well as to an end or goal. Both of these elements are included in Wolfensberger's 1972 definition:

> Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible. (*16, p. 28*)

This definition implies that we do normalize people, since an important element of normalization is to generate behavior which is as normative as possible. Obviously this second definition leads to a different interpretation of success. Success is now determined by the degree to which the goal of normative behavior is reached. The criterion for evaluating success differs depending on which definition is used. Success is based on the degree to which the process itself is normative under the first definition; it is based on the degree to which behavior is normative under the second definition.

Another major source of confusion is that normalization is often confused with some other popular concepts of the day. First, normalization is not synonymous with the developmental model. The basic concept of the developmental model is to approach every handicapped person with positive expectations that they can grow, learn and develop. The model does not claim that everyone can grow, learn and develop, but that each individual should be approached with that positive expectation.

The developmental model emphasizes the potency of the environment and the malleability of the individual. It emphasizes the objectives or goals of services rather than the process for reaching the goals. It specifies three goals of programs: (1) increasing the individual's complexity of behavior; (2) enhancing the capacity to cope with the total environment; and (3) enhancing of human qualities as these are culturally defined. The specific means which are used to reach

these goals are irrelevent to the developmental model. The means might be normalized or they might be non-normalized. The model focuses on the person, not the environment, nor the conditions that are used.

The second concept with which normalization is often confused is least restrictive alternative or least restrictive environment, which is a legal concept (*2*). My interpretation of least restrictive alternative is that alternative which provides the individual with the greatest freedom, with the greatest option to make choices. The criterion then, for least restrictive alternative, is the individual's options for choices, and not the degree to which a given setting approximates a so-called normal setting.

It is often assumed that the normalized alternative is, **ipso facto**, the least restrictive alternative. This assumption is a naive position which may or may not be true. It's an empirical question. The physical as well as the psychosocial freedom of the individual must be considered in assessing the potential choices which actually exist.

The third concept with which normalization is sometimes confused is the concept of individualization and the related concept of self-actualization or self-enhancement. The first, individualization, refers to meeting the unique needs of the individual. The second refers to providing the individual with a maximum opportunity for choice so that s/he can shape his/her own future to the greatest possible degree.

These concepts do not stipulate any specific conditions or settings. The person's needs are the preeminent consideration, and no assumptions are made about the means which will be used to meet the individual's needs. For example, if a given individual would choose not to participate in a group, or not to live in a normalized setting, this may be compatible with the concepts of individualization and self-actualization, but could violate at least some interpretations of normalization.

Finally, the concept of deinstitutionalization is often confused with normalization. Normalization is often used as a justification for deinstitutionalization. But according to the second definition of normalization (i.e., Wolfensberger's definition), it might be argued that some institution settings may be more successful in generating so-called normative behavior than would a community-based residential setting. Thus, the two terms are not synonymous.

Normalization Goals and Their Application

Normalization has been used primarily as a reaction against the differential treatment of handicapped people. The whole concept of normalization first evolved to neutralize the destructive tendency to generate deviancy.

Normalization includes at least three goals. The first and ideally, the most desirable outcome of normalization is to have the mentally retarded person become invisible, and to have him treated no differently from anybody else. The second, and somewhat less desirable outcome, is to have the mentally retarded person remain visible, i.e., identifiable, but treated no differently than anyone else. The third possible goal, generally considered the least desirable of the three, is to have the mentally retarded person remain visible or identifiable and treated differently from others, but only to the degree that is "necessary." Determining what is "necessary" remains a clouded issue. Is the person treated differently from normative patterns to the degree that is necessary to protect the individual's life, to protect society, to be economically feasible, or to be happy? The question is complex.

It is a fact that most mentally retarded people do become invisible. George Tarjan (*14*) claims that two-thirds of the mentally retarded school-aged population disappear shortly after they leave school. They are no longer identified as members of self-advocacy groups or anything else. They become part and parcel of society. Thus, the term "mental retardation" is applied to

a large extent as an explanation for scholastic failure.

Likewise, Conley (*4*) reports that 87% of mildly retarded men are productively employed, only 4% below the national average. So, most mentally retarded men are working productively, and only a small fraction of mildly retarded men are not employed. The figure is 33% employment for mildly retarded women, but even that is only 12% below the national average.

So normalization focuses primarily on the relatively small segment of the mentally retarded population that remains visible, primarily those people whose behavior differs most obviously from the so-called cultural norm. Severely retarded peple, profoundly retarded people, and multiply handicapped people are primarily the types of individuals who tend to retain a clear identity. What conflicts might exist about normalization relate specifically to these types of people. There is little disagreement with applying normalization tenets to mildly retarded persons, but there is considerably more conflict regarding the application of the concept to these more severely handicapped individuals.

Normalization has been applied primarily to institutional settings, settings which currently house primarily severely, profoundly and multiply handicapped populations (*12*). The role of the institution has, of course, become highly controversial, and normalization has been used extensively to challenge the legitimacy of the institution.

Normalization has also been applied in the area of education, where mainstreaming has become the focus of controversy. Part of the conflict relates to the desirability of specialized curricula as opposed to the general school curriculum. Some educators claim, for example, that forcing severely handicapped children to participate in regular school curriculum does them a disservice (*1, 3, 15*).

A third focus for applying normalization has been the sheltered workshop and the day activity center. These two service delivery mechanisms may become the next major target for advocates of normalization. They have been described as exploitative, fostering infantilism and failing to recognize the individual's potential for growth and development.

Thus, normalization has been primarily focused on these specialized settings, explicitly designed to meet the alleged extraordinary needs of mentally retarded people, as well as their families and society in general. Criticisms of these three settings have been based on the premise that they do not provide the best alternative to meet the needs of the population being served. By "best alternative," critics mean either the most normalized alternative, or the most effective alternative, or sometimes both. Criticism of these settings has also been justified on the basis that they violate ethical, legal or moral principles. Finally, criticism has been based on claims that these settings are not as cost-effective as alternative models.

Normalization is relative rather than absolute. That is, normalization is meaningful only when it is related to a specific subculture. Hence, what is normative for some people may not be normative for others, depending on the subculture or mini-subculture within which they are expected to live. Some of these subcultures may be normative in the sense that many people participate in them, and yet they may foster segregation and isolation from the mainstream of society. For example, nursing homes are normative, in that they are used by large segments of the population, but they foster segregation and certainly isolate their residents. Likewise, general medical and surgical hospitals foster segregation and isolation from the mainstream of society. They are also dehumanizing and affix labels to their residents. Senior citizen centers are another example. They have become normative but they also foster segregation and use labeling.

The question is this: Should mentally retarded people be segregated into these generic settings, or should they be assigned to less normative but more integrated and more humanizing options? Our society offers some subcultures which deviate significantly from the dominant normative patterns, yet they are available to most non-handicapped people. For example, communes are an available option to most people, although they are not exactly the normative pattern in our society. The same is true of multi-family aggregates or homosexual communities. Should such options be available to mentally retarded people as they are to non-handicapped populations,

even if they are not normative? That is, should all mentally retarded people be subjected to normative patterns? If not, under what conditions should they be provided alternative options?

As already suggested, some normative patterns foster regimentation and restrict individual freedom. The typical educational system is a case in point. Most schools are quite regimented, and they certainly curtail the pupils' individual freedom. Classrooms, transportation systems, many work settings, the military, etc., are all examples of models which confine the individual and impose certain restrictions upon him or her. Should mentally retarded people be encouraged to participate in these kinds of settings or should they not?

There are some who argue that imposing normative patterns on some severely and profoundly retarded people is dehumanizing and indeed, cruel. It is argued, for example, that some severely and profoundly retarded people may have a different rhythm of life than we do, and that their sensory preferences may differ from ours. Normative settings may deprive them of the most meaningful sensory experiences. Such considerations raise the question of what values predominate. Normalization? Individual choice? Developmental goals?

Justifications of Normalization

Normalization has been justified on a number of different rationales. Each of these rationales is based on implicit values, but since the values are seldom made explicit, the ensuing arguments are seldom resolved.

At least seven basic justifications of normalization can be identified:

- It is the preferred approach because it is inherently desirable. It is ethically and morally the right thing to do, based on an implicit humanistic value system.
- It is legally desirable, based on constitutional and statutory principles, including the principle of the least restrictive alternative.
- It is the most effective approach to normalizing people. This contention is subject to empirical tests. Thus, studies can compare the degree of success in fostering normative behavior using a variety of approaches, including normalization. The implicit value underlying this rationale is that it is desirable to be normal.
- It is the most effective approach to fostering development and growth, i.e., the best way to implement the developmental model. Again, this is subject to empirical validation. The implicit value on which this justification is based is that it is desirable to reach optimum development.
- It is the most cost-effective approach. Thus, expert witnesses testifying in courts of law have claimed that group homes cost less than institutions and are, therefore, more desirable. Again, this premise is subject to empirical validation. The implicit value is that economic efficiency is desirable.
- Normalization is the most beneficial option in terms of its effect on non-retarded people. Bengt Nirje noted that normalization is desirable because it helps non-retarded people to develop a better understanding as well as a greater acceptance of mentally retarded people (*8*). Parenthetically, the empirical data to date do not support the validity of this assumption, but again, it is subject to empirical tests. The implicit value in this argument is that understanding of mental retardation is desirable or that greater acceptance of retarded people is desirable.
- Finally, normalization is desirable because it produces the greatest happiness for the retarded individual. Again, this contention is subject to empirical validation, although evaluating happiness is a very difficult procedure. Again, there is an implicit value assumption; namely, that it is desirable for people to be happy. In short, this argument is predicated on a hedonistic value system.

Normalization then, raises several fundamental questions regarding the nature of mental retardation and society's response to handicapped persons. It has been used to criticize labeling. Yet do we really want mentally retarded people to become invisible? Some argue that labeling leads to devaluation and self-fulfilling and self-limiting prophecies. There are others, however, who claim that it leads to improved understanding and provides the basis for plans and programs. The elimination of mental retardation as a distinct entity might reduce or eliminate benefits to retarded people. Many benefits have been designed specifically as compensatory mechanisms to enrich or protect the life and welfare of mentally retarded people.

A similar question can be raised regarding advocacy. A very potent and effective advocacy system designed specifically to advocate for mentally retarded people has been developed in this country. Advocacy organizations successfully generate considerable political influence, help to modify public attitudes, press for human rights and so forth. If the target group of that advocacy effort were to become invisible, what would be the impact on the advocates? Likewise, if mental retardation were to become invisible, what would the result be on the self-advocacy movement? Without an identifiable group, how could retarded people join forces into self-advocacy groups? Furthermore, could integration and dispersal foster loneliness, isolation and loss of intimacy?

Eliminating the label of mental retardation may also impact negatively on research. Without an identifiable condition, it could become much more difficult to justify funds for research and to bring together researchers working on mental retardation issues.

Another challenging question relates to whether or not we really want mentally retarded people whose behavior is obviously widely divergent from that of their culture to be treated like non-handicapped people? For example, what are the relative merits of using generic versus specialized services? Of course, advocates of normalization stress the use of generic services. Yet, there is increasing evidence that generic services often fail to serve retarded people adequately. Frequently, they lack the sophistication and expertise to provide for the extraordinary needs of some retarded people.

What are the implications of eliminating labels for legal concepts which have special relevance to retardation, such as competence, diminished competence, consent, diminished responsibility and guardianship. These constructs have been developed to protect and/or to give preferential treatment to persons who have mental retardation.

What are the implications for entitlements of financial assistance to help compensate for handicaps? How about the implications for technology? Do we want, for example, to abandon or to avoid technological approaches which differ from the so-called normative approaches, even in the case of severely and profoundly retarded people? Is it desirable, for example, to discard the concept of a survival skill curriculum in favor of the standard academic school curriculum for severely and profoundly mentally retarded students? Should we avoid the use of chemical intervention, biofeedback or mnemonic training (i.e., training people in how to remember)? What about the application of prosthetic devices which are not normative in our society?

Finally, what do we want from the public? Of course, we want them to "accept" and "understand," but do we want them to accept behaviors which may be in gross violation of cultural norms without qualification, or do we want them to accept these behaviors because they understand that they are manifestations of mental retardation and, therefore, should be tolerated?

Concluding Remarks

In conclusion, I wish to propose some guidelines for the implementation of normalization. First, I suggest that mentally retarded people should be provided with normalized settings and patterns as defined by their own subculture, unless a deviation is: (a) more successful in fostering developmental goals; or (b) preferred by the individual mentally retarded person after a fair exposure to alternative choices. I am proposing, then, that the principles of self-actualization and individualization and the developmental model take precedence over normalization.

The second major conclusion that I propose is that we identify individuals as mentally retarded, when doing so is likely to be beneficial to the person, recognizing labeling as a mixed blessing. What I am proposing is that the benefit to the individual take precedence over philosophical principles regarding labeling and its alleged destructiveness.

The third tentative conclusion I am proposing is that we retain mental retardation as a visible category, and that we educate the public to its implications, stressing the positive elements. In other words, rather than implying that retardation does not exist and that there are no retarded people, I am proposing that we affirm that mental retardation does exist, that there are people who have mental retardation and that these people are valuable human beings.

I have attempted to present some unresolved and sometimes controversial issues. These issues all relate to normalization, an extraordinarily potent and influential concept in the field of mental retardation today. It is not my purpose to praise or condemn this concept. Rather, I hope this presentation will act as a stimulant for thoughtful deliberation.

References

1. Blatt, B. A drastically different analysis. **Mental Retardation**, 1979, **17**, 303-305.
2. Chambers, D. Right to the least restrictive alternative setting for treatment. In R. Ennis & P. Friedman (Eds.), **Legal rights of the mentally retarded**. New York: Practising Law Institute, 1973.
3. Childs, R. A drastic change in curriculum for the educable mentally retarded child. **Mental Retardation**, 1979, **17**, 299-300.
4. Conley, R. W. Mental retardation: An economists approach. **Mental Retardation**, 1976, **14**, 20-24.
5. Ellis, N. N., Moore, S., Taylor, J., & Bostick, G. **A follow-up of severely and profoundly retarded children after short-term institutionalization.** Tuscaloosa, Al.: University of Alabama, 1978.
6. Gorney, R. **The human agenda**. New York: Simon & Schuster, 1972.
7. Nirje, B. The normalization principle and its human management implications. In R. Kugel & W. Wolfensberger (Eds.), **Changing patterns in residential services for the mentally retarded.** Washington, D.C.: The President's Committee on Mental Retardation, 1969.
8. Nirje, B. Normalization and integration: Basic concepts. **Improving the quality of life: A symposium on normalization and integration.** Arlington, Tx.: National Association for Retarded Citizens, 1977.
9. Roos, P. Action implications of the developmental model. **Proceedings of a symposium on early intervention: Steps in the prevention of developmental handicaps.** Parsons, Ks.: Parsons State School and Hospital, 1976.
10. Roos, P. & McCann, B. Major trends in mental retardation. **International Journal of Mental Health**, 1977, **6**(1), 3-20.

11. Roos, P. Special problems. **Introduction to Mental Retardation**. New York: Charles E. Merrill Publishing Company, 1980.
12. Scheerenberger, R. C. & Jones, S. **Administrative problems.** Madison, Wi.: National Association of Public Residential Facilities for the Mentally Retarded, 1980.
13. **Summary of a report—returning the mentally disabled to the community: Government needs to do more.** Washington, D.C.: U.S. Government Accounting Office, 1977.
14. Tarjan, G. Natural history of mental retardation: Some aspects of epidemiology. **American Journal of Mental Deficiency**, 1977, **81**, 369-79.
15. Warren, S. A. What is wrong with mainstreaming? A comment on drastic change. **Mental Retardation**, 1979, **17**, 301-303.
16. Wolfensberger, W. **The principle of normalization in human services.** Toronto: National Institute of Mental Retardation, 1972.

Participant Discussion

MR. KRAUSE: I'd like to comment on one of the last provocative questions that you raised. I think from the government standpoint we are somewhat dependent upon various entitlements. I think if we look just at the last decade, if we were not able to pass specialized legislation, we would not have advanced to this particular point.

MR. ROOS: What I am hearing you say is in terms of the question: Should we do away with the term "mental retardation?" Are you saying that there would be some very negative, pragmatic consequences by doing that today?

MR. KRAUSE: I think we can hardly afford to do that at this point in time. We would find ourselves possibly with less funds to function and operate some of the programs which we feel are beneficial.

MR. ROOS: So doing away with the label could have detrimental consequences on the consumers.

MR. KRAUSE: I think at this point in time, yes.

MR. MARCHAND: There was an ad on T.V. last night about disability and disabled kids, and there was a baby in a crib. I said, "Gee, somebody is doing a good public interest spot here." And lo and behold, it wasn't a public interest spot. It was a paid ad by the United States Census Bureau urging the population to be frank in identifying disabled children and adults, on the basis that that data is going to be vital in developing future governmental programs for people with handicaps. There is a fear that the census data is insufficient because there has to be an awful lot of unreported handicapping conditions (epilepsy being a prime one) that are greatly under-represented in the census. I believe that that ad might have been pushed to alleviate some of that. There is serious question as to the validity of some of the census data.

MR. DYBWAD: What has the information given to the census bureau got to do with labeling? I think you are just screwing up the English language. This is not labeling—putting a label on the child. This is information that goes into a computer. A label is something that's **on** the can, not what's **in** the can. To me it's completely confusing. I just cannot see what it has to do with labeling when a mother says I have a child. . . .

MR. MARCHAND: I don't argue with you about that, Gunnar, but what about the mildly retarded child who was labeled retarded because of a placement in special education in school. That adult is now possibly raising a family, and does he want to identify himself as handicapped now when there is no particular reason to do so?

MR. DYBWAD: Why should he? Again, what has that to do with labeling?

MR. MARCHAND: It doesn't have anything to do with labeling. I'm just talking about the fact that the census data is not completely true or valid when folks who may have a need for some kind of supportive service in their adult life are unreported.

MR. DYBWAD: But, you see, that is a problem. I still say we are confusing things. I don't want anybody to be called mentally retarded and certainly not this word "retardate." That's absolutely unnecessary. Why should we call anybody retarded? But there is a problem when it's called epilepsy, you see. That has no relation to anybody being called an epileptic. So I really see your problem, but it's not a problem with labeling. It's a problem of keeping accurate statistics and so on. But I certainly feel that our strong campaign to change our labeling habits, not to refer to it, will only hurt if we insist that we cannot identify conditions such as cancer, epilepsy and . . .

MR. MARCHAND: I hear what you are saying, but until those individuals become comfortable with saying that they have a disability and expect no adverse repercussions from saying it, you people are going to continue to avoid saying it, just like the mother of a retarded person will continue to avoid saying it if there is no immediate value in saying it.

MR. ROOS: Let me respond to this whole labeling issue for just a second. I don't think it's too profitable for us to get buried in it for too long. But as I have listened to discussions on labeling for years, I have reached a conclusion which will not make me any more popular with this group. My conclusion is that the problem is not labeling. The problem is the negative connotations that are attached to specific labels.

You do not object if I call you an administrator, which is a label, or a lawyer, or a psychologist, or mother, or a violinist. These are all labels. Now, if I say to you I am a hypoglycemic, most of you probably would say "Oh, that's cool." I don't mind being labeled hypoglycemic. I do not insist that people say that he is a person who has hypoglycemia, just as I do not insist that you say that he is a person who has a degree in psychology, but does not practice now. The problem is that being called a hypoglycemic has no negative connotations, but being called mentally retarded does.

Although I am sympathetic with the thrust of what's being said, I feel the basic issue is that we need to change the connotations of our terms and avoid using other terms. Developing a phobic reaction to certain terms, I don't think, really addresses the issue. If my neighbor walks up to me and says, "What's the matter with your daughter, why does she talk so funny?" and I say to him, "She's mentally retarded," I would like him to say, "Oh, I see, now I understand. She's a lovely girl." That's where I think we should be heading. I don't think the solution is for me to say, "Well, you see, she's a person who learns slowly and hasn't developed language, and so forth." He's going to be thinking, "Now what in the world is he talking about?"

MR. COOKE: I tend to agree with that. There is a hockey player named Bobby Clark who is a very good hockey player, and a diabetic. It says on television that Bobby Clark is a diabetic. Well, that's the best thing that ever happened for diabetics. It is a great thing for Bobby Clark and so forth. People don't have a negative connotation of being diabetic. But if people said Bobby Clark was retarded, then that would be a different sort of thing. I tend to agree completely with Philip. It's not labeling individuals that's bad, but rather the connotations of the label. I think we can be inclined to magnify the damages from labels by doing these circumvolutions, by trying to use euphemisms at times.

MS. SCHAAF: To me, I think the label of MR or mentally retarded has been used so many times that people are used to it. Besides these, gobs of different names are being used as labels. I think once we get away from using mentally retarded, a lot of these handicapped people will feel more human. A lot of these people don't like the word retarded or mentally retarded, or any other label. If we can just pull all of our brainstorming together and come up with a realistic name that we could start using instead of MR or

mentally retarded, I think we could really make a good change in normalization. I think that is a basic start for normalization, that we start using a different category of names.

MR. FOSS: Your point is that the label has been so negatively used for so many years that you think a whole new term needs to be used?

MS. SCHAAF: Right, right.

MR. COOKE: You say that you should provide normative settings unless, and then you put down two conditions. One was that other settings may be more successful developmentally and, I'd like to ask, as judged by whom and through what means; and two, persons prefer other possibilities after alternative choices are presented. I'd like you to describe what sort of process you have in mind regarding alternative choices and so forth. Could you amplify those recommendations?

MR. ROOS: Thank you, Bob. I guess we could probably write a book on those situations because they are very complex. Let's take them one at a time. The first is that I'm suggesting that normative patterns, or that deviations from normative patterns, can be justifed if these deviations are more successful in reaching developmental goals. Now, I define developmental goals operationally as increasing the complexity of the individual's behavior, increasing his or her capacity to cope with the total environment (which includes the self, and the social and physical environment), and as enhancing human quality as defined by the subculture in which the individual lives. What I'm thinking of is this kind of situation.

Let us take, for example, a profoundly retarded person whose behavior repertoire is limited essentially to swallowing, breathing, and opening and closing the eyes. He is placed in a normative setting. We take him out of bed and put him on a couch during the day and we put him back in bed at night. We move the couch next to the table when we all eat, and there ain't much happening. Let us assume for a moment now that as an alternative model, we put him in a prosthetic environment in which his eyelids are connected to microelectrodes, microswitches, whereby he's now able to control various electrical devices in his environment, such as turning lights on and off, turning off the television set, or what have you. Let us further assume that using biofeedback techniques, we teach him that by twitching a muscle in the abductor gluteal for the right thigh he can control an electric vehicle, making it move forward, stop, or move back. Now, we propose that these kinds of modifications, those deviating significantly from the normative setting, are more successful in enhancing developmental goals. This individual is developing some control over his environment. His behavior now is becoming increasingly complex, and human qualities, in terms of interacting with his environment, are certainly being increased. So this is the kind of thing I have in mind, Bob. The definition would be in terms of rather operational descriptions of special behaviors.

The second point concerns the issue of choice. Let me give you a concrete example of what I have in mind there. Here's an individual who is living in an institution, and we are preparing him for the usual alternative of living in a group home. I would propose that we provide this individual with an opportunity to fully experience the group home by spending some time there. I would also encourage us to provide him or her with some other alternatives as well, sheltered apartment living or what have you. But in the final analysis if that individual said to us, "Hey, I have lived in the group home, I have lived in the community, and, man, I want to move back in the institution, that's my thing. In the institution I'm somebody, here I'm nobody, etc., etc." My proposition to you here is that I would then place that individual's decision above the principle of normalization.

MR. COOKE: But there are a lot of other alternatives besides the group home. How far do you pursue the tracking of alternatives?

MR. ROOS: I would try to provide the individual with as many alternatives as are realistic for that particular individual at that particular time in his or her life. Ultimately the individual should make the choice rather than the professional, and the choice should be made on the basis of choice rather than on the principle of normalization.

MR. KRAUSE: If we allow a person who is able to possibly function in a community setting to withdraw from challenges into an isolated, protective environment, we may not be doing well either by that person or by the tax payer who has to pay the cost.

MR. ROOS: Fred, are you saying that you would not agree that the individual should have the ultimate choice in these matters? You would suggest rather that the professionals should really make the ultimate choice?

MR. KRAUSE: No, I'm not saying that. I don't think that the professional or anyone has the prerogative or right to say that someone must live in a certain place or be forced into a particular kind of situation. I am saying, though, that at a point in the transition from an institution to the community, I doubt if anyone making the transition doesn't have thoughts or considerations that, "Hey, my friends are back there. I want to return to the institution."

MR. ROOS: Who makes the ultimate decision?

MR. KRAUSE: I'm just saying that the person may say he wants to return to the institution merely because he wants a safe haven, he wants the protection and isolation. We may very well not be doing him much benefit by saying that this is the only choice he has and that we will allow him to do it.

MR. ROOS: Okay. You are pointing out that there might be a lot of psychological factors.

MR. KRAUSE: Oh, I believe there are, yes.

MR. ROOS: That might work towards the individual's ultimate detriment.

MR. KRAUSE: That's right.

MR. ROOS: Am I hearing you right?

MR. KRAUSE: Yes.

MR. ROOS: Therefore, you are saying we should not be too quick to let the individual make these kinds of decisions?

MR. KRAUSE: That's right.

MR. ROOS: Then you added a second variable. I don't want it to go for naught, and that is the economic variable, right?

MR. KRAUSE: I think we have to be practical about it, and the economic conditions are a prevailing part of today's programs, particularly social programs. I don't believe that we can continue to expand on the medical institutional model in which costs are going to rise considerably over the next decade.

MR. ROOS: Okay. So you are saying you consider two variables, the psychological one that might be working against the individual's ultimate goals, and secondly, the realities of economics.

MR. FOSS: What if those costs were the same and the person had gone through some extensive counseling?

MR. KRAUSE: Then, of course, it's his choice. Suppose a person leaves a correctional facility and is out in the community and he goes to the probation officer and the judge and says, "I want to go back to jail." Is he allowed to do so?

MR. FOSS: Sure. All he has to do is violate probation.

MR. KRAUSE: That's right, or take a gun and stick some place up.

MR. ROOS: He has that option.

MR. MAUTHE: That's the only option available to him.

MR. KRAUSE: That's right. That's my whole point. He has to go to the extreme extent, which is antisocial action on his part to achieve what is basically psychological overprotection from the various problems he cannot face in society.

MS. SCHAAF: But there again you have to look at how long the person has been in the

institution. If he's been in there for a long time, one day he may become bound and determined to go back. But there again, we got to at least give him some time to readjust. Maybe we put him out into the community too soon. We have got to be able to look at these points and that person should be the one that makes the decision of whether to re-enter or to stay out, or to say something is wrong. He is the one that should be able to pinpoint his own decision.

MR. ROOS: It sounds to me like you are both agreeing that ultimately the individual must make the decision.

MS. SCHAAF: Yes, yes.

MR. ROOS: But you are also both saying you should not accept the decision prematurely, you should give the individual ample opportunity to experience the alternatives.

MS. SCHAAF: The professional, I believe, should not even have a say whether that person should be let back into the institution or stay in the community. This is the same way I feel about all residents that are admitted to all of these institutions. They should have the say at that time whether they even want to be put there.

MR. ROOS: Okay. I think you are agreeing with each other, but what I am hearing is that Valarie is putting more emphasis on the individual than on the profession. I think Fred is putting a little more emphasis on the profession.

MR. KRAUSE: No. If a person is truly a well-trained counseling professional, s/he will not make the decision in a matter that is a personal choice.

MS. KITT: I'd like to raise an issue that didn't necessarily come out in your talk, Phil, but I think is one that you'd be interested in discussing. It's in the prospectus that was sent out to us in advance of the conference dealing with the rights and responsibilities of parents. I am a parent of a retarded child. I just want to read what it says in the prospectus, and then make a couple of comments. It states that "The normalization emphasis on service provider philosophy and practice may have lessened both the need and respect for parental opinion and involvement. How is normalization ideology and practice affecting the families of mentally retarded persons?"

I think probably that's an area to which professional people have not given very much consideration. The normalization concept is very threatening and very frightening to parents. I know some of you can identify with what I am saying, but when you finally come to grips with the fact that you have given birth to a retarded child and this is going to be your responsibility from now on, you can hardly look forward to the day when this person will grow up and become an independent individual like your other children. You assume an attitude of protectiveness that most people call overprotectiveness. As the person grows, it's very hard to come to a point in time or realize that a time has come when you have to shed that protectiveness and let this person experience the dignity of risk, so to speak.

I think that one of the reasons the normalization concept has been threatening and frightening to parents is that they don't understand it. The more I learned about it, the more I began to personally accept it. Over the past six months we have begun letting our boy, who is now 15 years old, come home from school in the afternoon, use his own key, open the door and come in and spend an hour or so alone before anyone else gets home. You have no idea how frightening that was to me. There are neighbors around. He knows there is someone he can call on if he has a problem. But boy, thinking that he could possibly come home without me being there was a real educational process for me.

Anyway, I think it would be helpful if we could put more emphasis on realizing that parents do have a responsibility, but they have to know when to let go. They have to have

some kind of help in dealing with this whole process.

MR. ROOS: I'm glad you raised that point, Alice, because it is a difficult concept for parents to accept, and there is no question of that. I think parents get particularly anxious when they are faced with the rather extreme positions which they can interpret as the denial of the realistic limitations of some retarded people. Again, we must be responsive to the comments made earlier that mental retardation is an extremely heterogeneous condition, and what applies to the mildly retarded may not apply to the severely retarded.

MS. KITT: I have heard parents comment so often that just putting a child in a normal environment isn't going to make him normal. Many times we have gotten the attitude that that's what the professional community thinks. We worked many years, very hard sometimes, to accept the fact that he's handicapped and, by golly, you can't erase it overnight by putting him in a normal environment.

MR. FOSS: In my experience in working with service providers, I have seen many cases where they do not have the proper respect for where parents are coming from or for how well a parent knows the child.

MS. KITT: And very quick to assume that all parents are overprotective. By golly, you must be if you are a parent.

MR. MAUTHE: All parents are initially.

MS. KITT: Initially, yes. You are right. Some of us outgrow it.

MR. SOENNEKER: It's almost an identification of normalization with a civil libertarian position. It is another curious thing that occurs, particularly in a lot of direct service facilities. You know, the poor kid just turned 18, and by God, he's a constitutional adult and he can do any damn thing he wants. They would not make the same argument for their non-handicapped child coincidentally, but they would make it for a retarded person. That is, the parents get nothing to say about what happens to that kid and he should be allowed to do whatever the devil he wants. Sexuality is the classic thing that always comes up in this area.

I recall a speech that Gunnar gave up in Madison a couple of years ago in which he raised the question of what has happened to the common sense of professionals. I think there is something to be said for that. So frequently under the guise of idealistic kinds of concepts we simply lose track of all common sense.

MR. HEATH: How do you feel as a parent about your son or daughter banning together with other consumers in order to get support and feedback? How do you feel about that?

MS. KITT: I feel very excited about that. I prefer to think of him as becoming part of a group, at least for awhile, rather than being thrust out in the community on his own, because I think that would be a very lonely existence. I think that we choose groups of people that we like to associate with. We choose our churches because we have something in common with those people. I believe very strongly in your attitude about groups. It would be very satisfying to think that my boy could become a part of that. But if the day comes when he doesn't feel like he needs to be a part of that group, then I think he should have the right to live some other way.

MS. ROBINSON: I think it's important to point out that parents who are in ARC are what I classify as active parents. They are interested. They have obviously joined a consumer movement to bring about social change. There is also a large group of parents that I call reactive parents, and that brings us back to something I was going to mention earlier. Although Phil doesn't like to deal with the Wolfensberger definition of normalization, a lot of reactive parents like that definition. That is, they like their kid looking normal. They don't care if the kids are having a good time or if they are progressing. They simply are satisfied if the kid looks normal.

MS. KAPLAN: Does that meet their needs? I have spoken with some parents who are wanting their kids to look normal because they are embarrassed that the kids are . . .

MS. ROBINSON: Of course it doesn't have anything to do with the wants of the consumer. The state training schools are often classic. Staff walk around and tell everyone that they have one of the finest institutions in the country. Yet review teams come in from out of state and repeatedly say they do not have a very good institution. It may be a horrible institution. But the two things that they do at the institution is keep everybody clean, and have their teeth flossed three time a day. They have four dentists on staff, and that is normal and they like that. That's very popular, and it's very well funded. So I think that although we don't like to talk about that because that's not our goal, it is a major goal of the public when they think about normalization.

MR. ROOS: Well, that's a good point. I'm glad you raised it, and I'll react to that as a parent, too. I think there is some real validity to the statement that parents want their kids to look normal to decrease embarrassment. That's true, but in addition to that there is, I think, the very valid concern that to the degree that an individual looks and behaves in a very abnormal way, that individual is less likely to be accepted, to be understood, to be reacted to positively by the general public. So I see that as a very legitimate goal, to have people behave and look in a way which will be generally acceptable. If one of us were sitting here in our swimsuit or wearing a huge purple tie and drooling in our cup, I don't think most of the rest of us would like to engage that individual in a warm, cuddly and reinforcing conversation.

Normalization and Law

Cori Brown

"Assessment of the efficacy of the legal system to promote social change and implement an ideology (normalization) is fraught with controversy. Motives have been questioned, benefits weighed against dangers, future strategies debated, divisions created and new enemies identified."

In an attempt to make a problem more manageable there is often a tendency to seek single path solutions, to focus on an approach which assumes the obvious problems are the real ones. The tendency is to deal with problems and identify issues on a symptomatic level rather than searching for an underlying, often less obvious, real problem. My responsibility is to present a paper that stimulates a discussion of issues and implications of normalization as they relate to the law. My mission will be accomplished if my remarks and comments suggest to you opportunities, alternatives, new approaches and questions rather than answers.

To prepare such a paper, I first turned to the professional literature. I read and re-read books, articles, presentations, briefs, decisions and Law Review articles to try to formulate some sort of approach to identifying issues. Materials dealing with legal rights and legal procedures were helpful; materials relating to normalization perplexing. The more I read, the more confused I became. All my sources were somehow meshing into one. In checking footnotes and references, I realized I was reading the same thing over and over, different authors, different books and articles, but the same words in similar sequence to define the principle of normalization.

I then talked to people with much experience in this business, who had a commitment to and belief in the principle of normalization. I asked these people about the issues they felt should be raised in this paper. I talked to attorneys involved in major litigation, as well as people involved in the implementation of those decisions; to service providers trying to develop community programs, as well as recipients of those services; to people involved in legislative reform, and to educators. The results were astounding.

Contrary to my perusal of the literature, there seemed to be little consensus among these professionals regarding what normalization implied in relation to legal rights, and an even wider divergence in relation to the issues they felt should be raised at this conference. A sample of the concerns expressed included:

- "You need to talk about the problems, issues and implications of the day-to-day implementation of normalization."
- "People can't apply the principle to individual cases."

- "Do you know what some folks are doing in the name of normalization? People don't know what it means."
- "You need to point out the inconsistencies between some aspects of the principle and the court orders and legislation we have to try and implement."
- "People don't recognize the underlying values."

The only consensus appeared to be a lack of consensus. To raise issues regarding normalization as a principle and practice in relation to law becomes, by necessity, a task of illustrating contrasts, paradox and analogies.

Normalization has been expressed as a human management model. It has been defined in terms of processes and goals for social change. It implies certain methods and potential outcomes. It is based on implicit values. As people attempt to put an ideology into practice, the uniqueness of each situation leads to confusion about what should be done, and how and when it should be done.

Even when there is no apparent resistance to the original doctrine, disputes and controversy occur because of differences in interpretation. Some people appear to perceive the principle as implying rigid, inflexible structures and methods to be applied to all persons and situations in the same manner. Others appear to perceive it as a guiding principle that stimulates the creation of innovative services and service models with flexibility and adaptability.

Consequently, the question of whether or not the law supports the principle of normalization is, at best, an over-simplified approach to a complex issue. Certainly, the major court decisions and legislation on behalf of mentally retarded persons use the language of normalization, e.g., education in the most integrated setting and habilitation in the least restrictive environment. But as these court decisions, legislation and regulations have been implemented, numerous problems and conflicts have arisen. It is not surprising then, that what were heralded as major accomplishments, may be only "paper victories and hard realities" *(8)*.

Social Change

Assessment of the efficacy of the legal system to promote social change and implement an ideology (normalization) is fraught with controversy. Motives have been questioned, benefits weighed against dangers, future strategies debated, divisions created and new enemies identified. Even attorneys and advocates have become suspect as part of a system that has broken promises and destroyed hopes.

It is dissatisfaction with the status quo that leads people to use the legal system in the first place, and ironically, it is dissatisfaction with the legal system that leads people right back. Tired of losing endless battles and debates, people turn and return desperately to a system they little understand, to right the wrongs, end the sufferings and finally provide justice for those they care about so deeply. They continually encounter the powers and limitations of a system with its own purposes, procedures and language.

Lois Forer, in her excellent book, **The Death of the Law,** speaks of the inconsistency between the chronicled history of the law as the oppressor of the poor and powerless, and the persistence in the belief of the American promise of equal justice under law *(5)*. She expresses concern about the mistaken belief that a court can bring about widespread social change or that a judge can correctly decide complex matters of economics, biology or psychiatry. She states:

> Lawyers devise litigation to obtain Court rulings in order to effectuate what legislation has failed to accomplish . . . We cast these complex problems of behavior into the old molds of Constitutional issues, often obscuring the difficult economic, biological and social problems that intractably refuse to conform to the procrustean bed of the

> Bill of Rights . . . We expect the Courts on the basis of discrete individual cases to establish rules for the operation of innumerable institutions . . . Every question from the quantum of care for patients in mental institutions to the ecological dangers posed by the underground explosion of nuclear devices, is litigated in the courts. *(5, p. 40)*

We need to recognize that the law is inherently limited in its ability to promote social change. These limitations raise serious issues regarding the use of the legal system to implement normalization. First, the adversarial nature of the court system creates strong divisions between participants. Battling in the courtroom over one set of issues may well prevent future partnerships needed to address the resolution of the present conflict as well as other problems and concerns. It may even result in retaliation in other arenas.

Second, although courts may be able to bring to society's attention some of its most serious abuses, they are limited to considering individual cases. A specific set of facts is presented leading to a specific order of relief directly affecting only the people involved in the suit *(1)*. Lawyers must insure some way of measuring defendants' compliance with the decree, hence the need to quantify the underlying ideology. Attention is focused on more precise definitions and measurement tools. This, in turn, leads to difficult questions, such as, what are normalized environments for the people named in the suit? What is the least restrictive alternative? What methods need to be employed to make those decisions?

As difficult as these issues are by themselves, the difficulty is further compounded by the fact that courts are backward-looking. Asked to resolve conflicts after they have arisen, courts look to established precedent for the solution. As stated so well by Rutherford Turnbull:

> The law has a strong bias against innovation and change . . . The role of the lawyer is his creative use of precedent . . . to persuade us that which is new is really not new but an extension of old norms and beliefs. *(14, p. 143)*

The use of the legislative process to promote social change is also limited. The precision demanded in statutory language may inhibit the flexibility needed for practice and result in little allowance for individual differences and needs. Once a law is enacted it takes substantial time and effort to reshape it to conform to present conditions and knowledge. This time lag results in people's lives being regulated by antiquated laws. Thus, for example, while our society has always held liberty and equality to be two of our fundamental values, at times one or the other may predominate. In the 1930's much of the New Deal's social legislation (an attempt to promote economic equality) was overturned by the Supreme Court because it interfered with economic freedom. Recently, some courts and legislators (as well as much of the public) have become suspicious of the results of economic freedom; the anti-trust suits and the ever expanding area of governmental benefits are responses to a move toward equality.

Protection of Rights

The legal system has been concerned with protecting both the liberty and equality of mentally retarded persons in recent years. The cases and statutes requiring increased procedural safeguards for civil commitment and residents' rights in institutions are attempts to protect the liberty of mentally retarded persons. The essence of the least restrictive alternative doctrine is that the state must restrict the person's liberty only as much as is necessary to achieve its goal and no more.

The goal of equality is evident in such anti-discrimination legislation as Section 504 of the Rehabilitation Act of 1973 *(9)*, and the Education

for All Handicapped Children Act *(10)*. These acts are designed to give handicapped individuals not only an equal employment or educational opportunity, but in a broader sense, an equal opportunity to live a fulfilling, productive life. Unfortunately, in the movement towards ensuring equal opportunity for all citizens, the term "equal" has taken on different meanings. There are a number of laws which single out mentally retarded people as a group receiving special protection under the law. These laws appear to grant mentally retarded people freedom, but it is an empty sort of freedom. None of these laws promote equality with the rest of society. At best, they make one equal with others to whom the law applies.

Apart from their goal in terms of legal rights, do these protective laws carry out the principle of normalization? Certainly most of us aren't prohibited from marrying or childbearing or making important decisions on our own. Clearly, mentally retarded people aren't the only ones among us who have difficulty understanding marriage, raising children or managing money. If normalization calls for a life as typical as anyone else's, then these laws give retarded people advantages others do not enjoy, as well as restrictions others do not have. They are not consistent with either the concept of equal protection of the laws or of only necessary abridgement of liberty.

This effort on behalf of handicapped individuals grew out of the struggles for equal rights on behalf of racial minorities, and more recently, women. Until recently, the struggle for equality has concentrated on attacking the existing structures of society that impeded equality, and the solution sought has been to prohibit (or prevent) discrimination, e.g., with legislation related to education, employment and housing *(12)*. Civil libertarians often argue that this system of prevention does not go far enough; the effects of past discrimination place minorities in a socially disadvantaged position. They further argue that to achieve genuine equality, we must remedy the effects of past societal discrimination *(12)*.

The concept of affirmative action was formulated as a response to a dismal record of failure to promote equality. It takes into account past discrimination and requires remedies that attempt to equalize status by requiring entities to take positive steps to offer minorities equal status by giving them special opportunities. Sections 503 and 504 of the Rehabilitation Act extend these concepts to handicapped persons. Section 503 requires an affirmative duty on the part of federal contractors to hire handicapped individuals. Section 504 prohibits discrimination by recipients of federal financial assistance on the sole basis of handicap.

With the advent of this legislation, discussions as to the meaning of equal opportunity take on new dimensions. Because of the parallel aspects of the civil rights movement for black people and handicapped people, it is not unreasonable to assume that the goal of attaining equality for handicapped people in society may be sought through the legal strategy of affirmative action. Whether or not that strategy is compatible with the philosophy of normalization is an issue which must be fully explored.

Some people see normalization as placing emphasis on minimizing the deviancy of individuals, ignoring the fact that actions are also necessary on the societal level for acceptance of deviancy to occur. They would, therefore, take issue with the methods of affirmative action because of the potential for calling attention to the deviancy of the individual.

Others see the normalization principle as encompassing both the minimizing of deviancy **and** societal acceptance of deviancy, but with the latter being a hoped-for outcome in the distant future and not something demanding attention now. Therefore, they would see a consistency between the goals of affirmative action and normalization. There may be a dilemma, however, as to how both dimensions of the principle can be dealt with simultaneously. These issues and others will become increasingly important if affirmative action becomes the primary legal strategy in this area.

Institutional Care

The question of institutional care has perhaps been the most controversial area of the legal rights movement. David Ferleger and Penelope Boyd have noted that litigation in the area of mental disability law began with suits over civil commitment procedures (how one gets into the institution), then concentrated on conditions within the institution, such as the right to treatment (what happens once one is in), and is now addressing the question of the rationale for the institution (whether anyone should be in at all) *(4)*. A brief review of some of the cases will confirm this trend. The civil commitment cases such as **Lessard v. Schmidt** *(7)* brought about the introduction of due process safeguards, such as notice, the right to counsel and a hearing. Courts ruled that because of the conditions at an institution, commitment was a deprivation of liberty which required procedural protections against unnecessary commitments.

With **Wyatt v. Stickney** *(15)*, the conditions at the institution became the subject of lawsuits. The court in that case found that residents of the institution for the mentally retarded had a right to habilitation in the least restrictive alternative. To implement such a right, the court formulated standards to raise the quality of institutional life to a constitutionally acceptable level. The underlying objective was to improve the institution, and although the court decreed that residents were entitled to habilitation in the least restrictive alternative, the judge appeared to have little doubt that adequate habilitation could be provided in the institution. Other cases either followed Wyatt's reasoning or developed other rationale for ordering improvements at state institutions.

Six years after the standards in Wyatt were issued, **Halderman v. Pennhurst State School and Hospital** *(6)* was decided. Here the institution was on trial, literally (since Pennhurst was the first named defendant) and figuratively (since the plaintiff's lawyers hoped to show that any institution, by its very nature, could not provide adequate habilitation). The judge found that conditions at Pennhurst violated the residents' rights under the U.S. Constitution, and federal and state law, and ordered the institution gradually closed and community placement found for all residents.

As this cycle progressed, the necessity for involvement of professionals became paramount. In addressing commitment, the subject matter concentrated on a legal process. In the development of a theory to the right to treatment/habilitation, social goals were translated into legal concepts, i.e., "right to the least restrictive alternative," and "right to freedom from harm." In order to frame such legal concepts, attorneys needed to know what could and should be done to provide adequate habilitation. Thus, the process of educating the attorneys and eventually the courts began.

Professionals told them about enlightened principles as they applied to comprehending and solving the problems of mental retardation. They talked about the developmental model, normalization, individualization and self-actualization *(11)*. The professionals also told them about processes to implement these principles and such things as individual program plans, interdisciplinary teams, training methodologies, staffing patterns and community alternatives. The attorneys believed them. The decisions and standards established in right to treatment/habilitation cases reflected the principles and methods expressed. As Dr. Roos pointed out:

> Although much of the litigation has been bitterly contested . . . the conflict was almost always over the **feasibility** rather than the **desirability** of the reforms advocated by plaintiffs. *(11, p. 615)*

With the advent of Pennhurst, the movement shifted from considering the conditions in institutions to questioning their very existence. Whatever had been viewed as some sort of consensus quickly evaporated. The backlash many feared seemed imminent. Accusations and condemnations were hurled at attorneys, professionals and parents alike. What attorneys and others interpreted as a logical legal extension of what professionals told them was best for mentally retarded persons, was anything but logical to many.

We have only to listen to the reaction. We hear assertions that the reason Judge Broderick

reached the decision he did and ordered such sweeping relief was that the expert witnesses were wrong. We hear defendants experts' testimony, six years after the initial Wyatt decree, asserting that the expert opinions underlying the Court's least restrictive alternative/deinstitutionalizatien standard were "fully recognized as unwise at the time by those most knowledgeable in mental retardation" *(13)*. We hear pleas for more research, calls to study the matter more fully.

We hear stories such as the following, related by David Ferleger, the plaintiff's attorney in Pennhurst. As Judge Broderick was developing his order for relief in that case, he asked David if there was a need for some sort of hearing for class members before placement in a particular community residence. David deferred to his "experts." The first he contacted replied, "Of course. We have to ensure a freedom of choice and the individual's knowledge of and consent to the community residence he will be entering." The second one stated, "Of course not. When I look for, and make a decision about a place to live, I don't go through a hearing" *(3)*.

Summary

We are at a crossroads. References are made to the first wave of litigation and the implications for the future which raise new and more controversial issues. People speak of deeper divisions and more difficult battles ahead. Strategies on how to deal with reactions, backlash and resistance are being discussed.

These conflicts and issues should not have been unanticipated. They did not result from Pennhurst, or other "legal" interpretations of normalization, but rather have been hidden beneath the rhetoric of the past decade. The language of normalization for many has focused on the processes, not the implied values. We have been busy defining, labeling, and categorizing environments, clinical interventions and social interactions. The questions asked reflect our preoccupation with the methods.

Many have been asking others "how" when they should have been asking themselves "why." To announce belief in a philosophy without exploring its value base is to deny the moral and ethical implications of such an ideology. To avoid dealing with interpretations of right and wrong, good and bad, results in asking the wrong questions and arriving at simplistic conclusions.

We are being asked for more precise definitions, criteria and measures for designing remedies, for legislative reform. We are being asked for answers when we have yet to ask the questions. We need to carefully consider the nature of the questions. In the words of Burton Blatt:

> There are two kinds of questions, one that seeks an answer and one that gives an answer. And, further, there is a third kind of question, a question that both seeks and gives, a question that's both cynical and hopeful, both not curing and eager for new evidence and a way to retreat from dead center. *(2, p. 176)*

References

1. Bazelon, D. L. Preface. **Stanford Law Review,** 1979, **31**(4), 541-544.
2. Blatt, B. **Exodus from pandemonium; human abuse and a reformation of public policy.** Boston: Allyn & Bacon, 1970.
3. Ferleger, D. Speech presented at the Practising Law Institute Seminar. Denver, Colorado, January 10, 1980.
4. Ferleger, D., & Boyd, P. Anti-institutionalization: The promise of the Pennhurst case. **Stanford Law Review,** 1979, **31**(4), 717-752.
5. Forer, L. **The death of the law.** New York: McKay, 1975.
6. **Halderman v. Pennhurst State School and Hospital.** 446 F. Supp. 1295 (E.D. Pa. 1977).
7. **Lessard v. Schmidt.** 349 F. Supp. 1078 (E.D. Wisc. 1972).
8. Lottman, M. S. Paper victories and hard re-

alities. In V. Bradley & G. Clarke (Eds.), **Paper victories and hard realities.** Washington, D.C.: Georgetown University Health Policy Center, 1976.

9. Public Law 93-112. **Rehabilitation Act of 1973.** September 12, 1973. U.S. Code 29, Sections 700 et seq.
10. Public Law 94-142. **Education for all Handicapped Children Act of 1975.** November 29, 1975. U.S. Code 19, Sections 700 et seq.
11. Roos, P. The law and mentally retarded people: An uncertain people: An uncertain future. **Stanford Law Review,** 1979, **31**(4), 613-624.
12. Sedler, R. A. Beyond Bakke: The constitution and redressing the social history of racism. **Harvard Civil Rights—Civil Liberties and Law Review,** 1979, **14**(1), 133-169.
13. Summary of Partlow Review Committee Report. In the Motion for Modification, Wyatt v. Hardin, CA No. 3195-N (M.D. Ala. Oct. 20, 1978).
14. Turnbull, H. R. Through and beyond the history of the developmentally disabled. In J. R. Paul, R. Wiegernik, & G. R. Neufeld (Eds.), **Advocacy: A role for DD councils.** Chapel Hill, N.C.: Developmental Disabilities Technical Assistance System, 1975.
15. **Wyatt v. Stickney,** 344 F. Supp. 387 (M.D. Ala. 1972).

Participant Discussion

MS. KAPLAN: Questions that I have been dealing with in our courts in Oregon relate to a recent reinterpretation as to who does and does not fit in the mental retardation category. There was a mass exiting from the institution recently based on a ruling that they no longer could be classified as mentally retarded, as well as the least restrictive alternative argument. The attorneys and the courts are saying that as an advocate for normalization, I must be in favor of that. But, I am also the person who does the follow-up for the people who are going out in this dumping process, and seeing these people under the bridges and in the jails.

The state institutions have not taken the responsibility for preparing these people to leave. You just can't institutionalize somebody for 20 years and the next day tell them that they are not retarded anymore and are ready to leave. But how do you affect that process? The courts are saying these people have to be out, and the institutions are saying they can't keep them because they will be liable for lawsuits.

MS. BROWN: Certainly a lot of disputes have occurred because of things that we have wanted. Laws and policies that address deinstitutionalization result in a lot of debate about who makes decisions and, of course, what is there in the community. The most blatant example of such a movement in this country is the one which is trying to change statutes for limited guardianship. None of them are going to work unless community alternatives are there, unless advocates are there, unless support systems are there.

MS. KAPLAN: But I don't understand why the laws can't reflect an insistence that before anyone is affected by a law, certain steps have to be taken. For example, the institution will be responsible for giving special training, this training will be evaluated, and when it is considered effective, that person moves out. Then those that are prepared will go out, and those that are not prepared to handle the community will not.

MR. KRAUSE: It is not a question of desirability, it's feasibility. In many states they have not reached a point where the service

delivery systems or the array of comprehensive community services exist. Certain states in particular have for many years been very slow in the development of community services.

I may have misunderstood or misinterpreted what you were saying about how we are not making progress. But, I think we have been making tremendous progress. As one who has been in the field for over 25 years, knowing the limited services we had at one point and now traveling around the country and examining data and communicating with many people, I believe that growth has occurred in the last decade, a decade in which legal rights have been a principal push by the various frustrated and concerned parties, including parents who have said they will no longer accept the brutality and abuse of the institution, and the warehousing.

Now, absent from this conference, unfortunately, are some of the superintendents who have been faced with some of these questions of legality, and they would be the first to say that they wanted this change to take place. But, the point is that the growth has and will continue as a matter of supply and demand in terms of how much push there is for some of these services.

MR. DYBWAD: The return of people to institutions who have been allowed to leave is minimal in some states. With respect to our discussion yesterday, I believe we can afford to provide maximum leeway to anybody who wants to come back and wants to go out again, and then maybe come back a second time. We are dealing with complicated human problems. You don't tell a guy who has a cardiac problem that he can't be admitted back into the hospital because he had his chance, you know. So why should we make such stupid decisions with mentally retarded persons?

But the point I am making at the moment is that in some states the return of people to the institution is a tremendously important problem. In our state, it's not at all. I was very interested that you reported this activity with the prisons and so on, and I wondered what kind of people you took in in the first place.

One of the difficulties is that we have something we call mental retardation institutions which used to be catch-alls for a widely varied population in some states. We had sizeable numbers of children with autism placed there, who certainly constitute quite a different group of people. So I think that we maybe can learn from this if we have a little bit more exchange of information. But, I just wanted to say that you need to anticipate that we may get varying answers when reports are based on the experiences of different states. I think what we need to consider is: what kind of accountability and legal responsibility do we have for the people that have left the institution?

MR. NOBLE: Going back to the limitations of the law to court decrees, I think the law has certain expectations about the ability of the other institutions to do their job. And looking at the history of our implementation methods in and around these class actions, that will be where we are going to be struggling, I think, for the next 20, 25, maybe 2,000 years. If you look at the history of our common law solutions for these populations, we have typically institutionalized for purposes of assuring long-term outcomes, assuring that certain very difficult types of problems in the community will be looked after. The laws establish all sorts of institutional solutions for dealing with difficult populations. But, I don't think the law understands or can really control the hurly-burly of community life.

As Gunnar pointed out, each state is different, but even within states, each community is different and it's unpredictable as to what any set of agencies or any set of professionals will do. It's just unpredictable. I think that's the dilemma, because in the institution you could stick it to an individual supervisor because s/he was legally responsible for taking care of this individual for the rest of his/her natural life. Now we are trying to put people into the least restrictive alternatives with the expectation that somehow these least restrictive alternatives will take care of the person.

I'm not as optimistic as Fred is about how far we have come. I think we have come a great way in terms of ratification, but I don't think we have come out on the community level beyond where we ever were. What we deliver with assurance is a work-up and a referral, a little bit of information, some of which

is accurate. But I think the name of the game is ping-ponging. When I was a case worker, the trades you had to work out between agencies used to drive me crazy—"I'll take care of your client if you will take care of mine." I think that continues, and I don't think courts understand (nor do I think the masters or the receivers fully understand) the limits of the community network of services. So there we stand,with the decisions requiring least restrictive care alternatives, but no real legal instruments to enforce assured outcomes.

MR. SOENNEKER: I wanted to take a different tack if I might and pull this thing back to the core of Cori's presentation. I thought she make an incredible statement near the end of her talk regarding the need to analyze the ethical or moral content of beliefs. Now I feel that with normalization, as our technicians are implementing it today, there are two completely separate and distinct beliefs that are operating, and they go back to a point I was trying to make yesterday in terms of the difference between respect and beneficence. For one group of people, the severely and profoundly retarded, we attempt to implement beneficence. We attempt to do good, but we do an incredibly bad job of it. We spend a lot of our time doing that for them, and all you have to do is look at the history of abuse in our institutions to know exactly what I am talking about.

On the other hand, for the mildly retarded, we are implementing another set of beliefs that talk about respect and least restrictive alternatives, etc. Mildly retarded persons are getting completely screwed in the service system because their needs are not being met. In other words, the normalization ideology contains, in my view, two inherently contradictory sets of beliefs for two inherently contradictory groups of people. That point in your talk struck me and I would like to begin to examine normalization and what we are doing at that level.

MS. BROWN: I would really like to respond to that, because I picked up on your statement yesterday obviously in anticipation of today. We talked about labeling in lots of contexts, but I'd like to bring it back to a value base. I struggled with talking about protective services and how to do that, because I know that when we talk about the legal system that's one of the first things that people think of.

The analogy that you are giving is the analogy I was trying to work through for myself. What is it that we are doing as a society in terms of how we perceive individuals who are handicapped? We have got to take care of people who cannot take care of themselves. But how do we balance the doctrines of the general welfare and protectiveness when we talk about individuals? I think Phil Roos has very well pointed out, in an article in the **Stanford Law Review,** the need for professionals to start talking about capabilities and to look at people as people. We haven't done a good job of protecting people in terms of their capabilities.

MR. NOBLE: Unlike the other professions, the lawyer is a peer advocate. First and last comes the interests of the client. They don't go crying about the system they find themselves in with their client. Their job is to manipulate the system that exists, the categories, the labels if you will, to assure their client's entitlements and rights. That is the good they give, to listen to the client from wherever s/he is.

Now, I don't know whatever happened to case workers in the process of becoming case workers, but the case workers of today don't seem to be the advocates that I remember. They seem to be much more bureaucrats, implementing the interpretation of the regulations that are imposed by their bosses . . .

MR. DYBWAD: Case managers.

MR. NOBLE: Case managers, whatever. The thing is that the rehabilitation system is a very adaptive system. It never gave me any problems when I was trying to get college educa-

tion for some of my clients. So I had to bring in a psychiatrist to classify them as behavioral disorders. But they got into the rehabilitation system, and I got the funds to support college education. But at least an outcome was assured that was consistent with their real capabilities and desires.

Now, I just think that normal is competitive. Normal is hustling. We all have to do it. Our clients are going to have to do it. The thing that we can offer to our clients, I think, is that we can hustle for them, and we can teach them to hustle for themselves in a system that's ever changing. So CETA's got a lot of bucks. Okay. Rehabilitation didn't do that well this year. Well, what you do is hustle the CETA bucks for your clients and so forth. This is not going to be a perfect system, but I think that in the hustling process, the competition, you come out with a rough measure of equity, perhaps. Maybe even cost effectiveness, depending upon how good the players are in the system.

MS. KITT: I think somehow we have to get into the mood of individualization more, considering people as individuals. I think we are still hung up in thinking of all retarded people as a group, and what's good for one is good for the whole group. I think this applies to normalization as well. I don't think we can assume that either all retarded folks need guardianship or all of them don't need it. Well, my child may need it. Another may not.

I think one of the greatest things that's happened in our whole system is the development and implementation of the individual education plan and program plan. I think we have seen a real change in the structure and the behavior of services as a result of that, and we need to apply it to the very basic idea of normalization in determining how the law should apply to these people.

MS. KAPLAN: I'd like to reflect on all this conversation from what I guess might sound like a consumer, because I think it's important to focus back on what we are talking about. I hear how the laws are all interpreted negatively in terms of their impact on handicapped people. I hear how we have to label somebody a "behavior disorder" in order to get services for them. I hear talk about mentally retarded offenders. We are saying that we have consumers living in group homes that they have had little choice in getting into, doing programs in which they have had no input, getting labeled in order to get services, doing a day plan that they have to be in because they have to be out of the home five hours a day, learning work that can't be translated into regular employment, and if they make too much money, winding up getting the services they need cut off. What are we all talking about?

We are looking at normalization for the 80's now and what we are going to do about it. How can we change some of this total negative impact on the consumer? I hear no positive expectations. These people cannot survive. We have got to start working at changing how we are talking. It's not okay that we call people "behavior disorders" to get a service. It is not okay that rehabilitation will not change the kinds of training they are giving. It's not okay that these people are winding up in court. The consumer doesn't know how to say, "I don't know how I got here. I don't want to live where I am living. I don't want to do useless work. Nobody is translating anything to me."

I think we have some responsibilities here, and I want to make it known that I insist that some people start to take this responsibility. You have got to see how what you are talking about is actually affecting the consumers. I don't want to come across totally negative because I really do agree that the laws have had a positive effect in a lot of ways. I have seen tremendous growth in the whole concept of normalization, but what we were trying to make clear yesterday was that we have not gone far enough. We have got to stop saying how great we are at this point, and we have got to go to a point beyond and change some things and go forward. I think we have got to.

MR. DYBWAD: I absolutely am serious that the major change agents of the future are going to be the consumers themselves. I was amused here today that people said we need to educate the lawyers. I think the lawyers have a lot to teach the psychologists who have failed the consumers, as well as a lot of the social workers. I don't want to go on an anti-professional binge. I make my livelihood by training pro-

fessionals, but don't forget, it was the Child Welfare League of America, the National League of Social Workers, the Family Service Association, all of which were years behind the American Dental Association in recognizing there is even such a problem as mental retardation. The professionals by and large have failed us. If you look at what is printed in text books today, if you look at what young people still learn, whether they are in pediatrics, psychology, or social work, the kind of stuff they are being fed is so negative.

I really feel that the confrontation which is going to come by the consumers is something I have hope for because it will confront the professional community with a need for change. I am an optimist. I think for the Alabama Ten, it's the last hurrah, because they are bankrupt in the negative attitudes they show by saying there are human beings you can't train, who you can't do anything with, throw them in the wastebasket and so forth. I'm an optimist, but I think the change is not going to come out of the professional associations who have failed us miserably.

MS. KAPLAN: I had to justify and be very angry with someone in this room who asked last night why the helpers for the consumer movement are here. I wish I knew. I think I'm starting to figure it out. If I were here representing an agency, I would probably feel very confused and be unable to respond openly and honestly. The fact is that I am not tied to anybody in my role today and I feel close enough to the consumers to believe that I am not going to screw them when I open my mouth, though I have been told that I have done that. I don't know if anybody can get out of their roles enough to see, to just be kind of pure about what we are looking at. I think that we need to do that, because if I had to somehow represent some agency that I came from, I don't know that I could make any statements. Maybe that's a conscious or unconscious kind of struggle that everyone in this room is going through. I feel very glad I'm not tied by any money or agency boundaries or anything except impact right now. I think that's a hard thing to do, but I think we are going to need to do that if we are going to look at the issues.

MS. SCHAAF: I want to bring up something about normalization and the law and judges and courts. I have had a similar experience myself when I have gone through courts. What I found through my experience was that the court-appointed lawyer or the judge that is hearing your case don't really let you in on it. They will just come up with some ideas or something that has to be dealt with, and then they will bring it to you later and say we recommend this or we would like you to do that. But, what I felt during my time in that court was lost and sort of confused, because they didn't really bring me in on the whole planning or on the whole deal in the court.

Other times I was asked, if I knew what court is, and if I knew what they do in these proceedings, and I said, "Yes, I do now." But when you actually go through it, they block half of that out. They don't really let the consumer know what is really happening. This judge, and it wasn't his fault, was soft spoken and I could hardly hear him or even understand what he was saying. You have to learn to look at all of these aspects.

You also get a lot of individuals that are court committed and they don't even go to court sometimes to find out why they are court committed. We get a lot of individuals that have done some wrong in the community, and they are told, "We don't feel that you can survive in court or understand what is going on, so we will put you in the institution to fulfill your punishment." But, I wish that they would be able to make the consumer feel normal like other human beings.

MS. BROWN: I think Valarie has very eloquently talked about the bottom line in terms of the problems in the legal system. The attorneys' responsibility is not to look at what someone else thinks is in the best interest for somebody. Their responsibility under their canon of ethics is to talk to their client and find out what it is he or she wants, to learn how to communicate with that client, so that they can communicate what it is that is happening, what possibly could happen, and represent those things that the client wants, whether they agree with it or not. This often does not happen for a lot of reasons.

MS. SCHAAF: There is just no communication, it doesn't seem.

MS. BROWN: Some of the results of some of the court cases have been a requirement that the individual has to be there, that they cannot hold a proceeding without the individual, and that this has to be a court proceeding. There has to be an attorney who is there to talk about things that Valarie is talking about. A judge said to me, "That doesn't happen in my courts. Granted our statutes aren't too great, but that would never happen here." Yet, I could cite to him five times that it happened there. I mean, it's a real problem. I think it's something that we are starting to make a little progress with. But, I think your points are so well taken and something that we really have to consider and look at.

Those attorneys who could do what I suggest have a lot to teach us about "best interest," whether we are advocates or social workers or psychologists, whatever "helping profession" we are in. We are not there as best interests, but we are there to try and understand what it is that the person wants, and to try and fight to find a way to make that happen for the person.

Normalization and Economics

Ronald W. Conley
John H. Noble, Jr.

"The sometimes perverse interactions among programs stand as a warning to well-intentioned persons to resist the temptation of rushing ahead with simple policy change prescriptions. The more sophisticated policymakers and lobbyists know full well that yesterday's reforms are very often at the root of today's problems."

The provision of normalizing services to mentally retarded persons frequently involves initiating or expanding community programs that are tax funded. In these times of taxpayer discontent, considerable legislative resistance to funding these programs is likely to be encountered, particularly if the costs are uncertain.

The goals of services to mentally retarded persons, and the philosophies of "normalization," "deinstitutionalization," and "least restrictive care" must be grounded in how services affect both the well-being of the persons being served and the costs involved. For example, if a mentally retarded person is moved into a different living situation, the reason should not be because the place is smaller, or less restrictive, or more normalizing, but because it increases satisfaction with life. If increased costs are involved, then it must be shown (or at least believed) that the resulting increase in personal well-being exceeds the increased cost of achieving it.

Assessing the effects of services on well-being can become very complicated. Often the goals of services will conflict with one another. Moving the person to a less restrictive location will usually increase hazards to personal safety and increase the likelihood of undesirable events, such as assault or out-of-wedlock pregnancy. In addition, the person's possible desire to avoid work must be weighed against the social responsibility that a reasonably able person has to work and contribute to self-support. Finally, although difficult to avoid, it is very important that we not impose our values of normalcy on mentally retarded persons any more than we would permit others to impose their values on us.

Community-Based Care

The trend in services to mentally retarded persons for over 20 years has been toward less reliance on institutional care and increased reliance on community-based care. This trend has been motivated by intense dissatisfaction with institutional care. Unfortunately, it has not been accompanied by a clear understanding of the goals of community-based care or how to achieve or measure these goals.

A more simplistic goal has often been selected, that of depopulating large public institutions. Sometimes mentally retarded persons have been placed in nursing homes that are as restrictive as the institutions they left, or more so. Sometimes they have been placed in community residences with little or no provision for transportation, rehabilitation and other necessary services.

These deficiencies resulted, in part, from a failure to understand what the movement to community-based care required. It did not require the abandonment of all institutional care; rather it required the creation of many alternative treatment modalities. Yet, increasing competition for the nation's stock of housing may cause a critical shortage of normalizing community residences for mentally retarded persons. Datel, Murphy, and Pollack *(3)* clearly documented how large a role housing plays in the successful deinstitutionalization of mentally retarded and mentally ill persons and juvenile offenders.

These investigators found that nursing homes were prescribed relatively infrequently as an appropriate placement for mentally retarded and mentally ill people. More frequently prescribed were placements in foster homes, halfway houses, group homes, boarding homes and residential hotels, or with relatives or guardians. All of these alternatives usually cost less than nursing home care. These first-choice housing and care modalities, however, were often unavailable and led to many compromises in the choice of housing for deinstitutionalized persons.

Although community-based care is usually defined by the type of living arrangement (e.g., group home, halfway house, supervised apartment), it must be emphasized that each should provide appropriate vocational, social, medical and transportation services. Unfortunately, we have not as yet developed a system that ensures provision of needed services in a comprehensive or coordinated manner in community residences. Responsibility for all services in institutions is vested in one authority, and funding is mainly derived from one source so that the provision of needed resources can be easily arranged if funds are sufficient. Once a person leaves the institution, however, funding often must be pieced together from a wide variety of sources, e.g., income maintenance from Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI), medical care from Medicaid or Medicare, social services from the Social Security Act Title XX program, and employment services from state departments of vocational rehabilitation or state employment services. Generally, no single agency has the responsibility or authority to ensure that all needed services are given. Moreover, many operators of community facilities are unaware of all of the available programs or of how to go about obtaining needed auxiliary services.

The Intermediate Care Facilities for the Mentally Retarded program (ICFs/MR) under Medicaid avoids many of the difficulties of providing comprehensive and coordinated services, as it can provide most needed services through a single open-ended funding source. Not all mentally retarded persons, however, are eligible for services in ICFs/MR. Major deterrents to development of ICFs/MR are the requirement that the states share about half of the costs of ICFs/MR with the federal government, and the unclear limits as to the types of services that can be purchased with ICFs/MR funds. In contrast, if basic room and board costs are paid for out of SSDI or SSI benefits, there are no matching requirements or restrictions attached to these funds.

Despite the convenience of the ICFs/MR approach, it does present dangers. Placing all authority for decisions about individual services into the hands of a single authority, paying for all services through a single funding source, and adopting a medical model that implicitly assumes something is wrong with the individual, may lead to creation of a **de facto** institutional environment in a community-based facility. In fact, the premises underlying the concept of normalization would seem to be inconsistent with the use of ICFs/MR facilities for many mentally retarded

persons, in that it is more normal to obtain needed services from generic agencies than to be placed in a 24-hour care facility funded by a single source.

Despite the length of time in which community-based care has been developing and the strong convictions of its advocates regarding its merits, little is known about the benefits and costs of its different modalities for mentally retarded persons. Research and evaluation are in process, but it will be no easy task to interpret the data that are being collected. If one follows the following guiding principles, however, it may be possible to avoid foolish mistakes.

- **All costs incurred in a particular residential modality must be identified, regardless of whether they are incurred in one or several budgets.** A common mistake made in comparing costs of various facilities is to compare the cost of a facility providing a full range of services with one providing only limited services.
- **The cost of a particular residential modality must be compared to the costs of its meaningful alternatives.** Even if the cost of a community residence is high, it may still be less than the cost of institutional care which can run to $60,000 or more per year.
- **One should never look at costs without simultaneously examining the benefits of each residential alternative.** Even if community care is more expensive than institutional care for some persons, it may still be justified from an economic standpoint if the increase in cost is more than offset by the increase in benefits, e.g., if the deinstitutionalized person is able to engage in remunerative work, or can enjoy greater life satisfaction.
- **When comparing costs and benefits among different facilities, we must be careful to compare costs and benefits for the same types of residents.** We cannot compare the low cost of a community facility serving persons that require minimal supervision with the high cost of more restrictive facilities serving persons that require extensive developmental or medical services. Nor should the low cost of an institution providing primarily custodial care be compared with the high cost of community facilities offering extensive services.
- **Definitive conclusions about the value of normalization or deinstitutionalization can be made only if those persons being placed in the community are placed in residential facilities that appropriately meet their needs.** One can always make community-based care look bad by comparing the costs and benefits of caring for persons placed in institutions with the costs and benefits of placing them in inappropriate community living situations, e.g., nursing homes or inadequate board and care faciltities.
- **If data on benefits and costs are incomplete or subject to a wide margin of error, any findings must be appropriately qualified.**

Public policy is at the crossroads with respect to the provision of normalizing care in least restrictive environments for the mentally retarded and developmentally disabled populations, as well as the physically handicapped, mentally ill, and elderly populations. Several circumstances are converging to create ferment and increasing pressure on policymakers to take positions for or against further development of community-based care facilities.

First, there is rapidly developing support for removing persons from restrictive environments in institutions and nursing homes, as well as legislative mandates requiring it. Many people believe that community-based care is less costly as well as more normalizing than institutional care. The increasing tax burden for all social programs, however, has created political barriers to its further expansion, largely because of the substantial capital and transitional costs involved in developing community-based care.

Second, the perceptions about what constitutes appropriate care and treatment are unequally shared by the three branches of government (legislative, executive, and judicial) causing conflict among them on a number of issues. Similarly, professionals, caretakers, unions, family mem-

bers and the laity also have not assimilated the rapid changes in perceptions that have occurred concerning appropriate care and treatment for severely disabled persons.

Finally, the multiplicity of programs, sometimes overlapping and duplicative, makes it difficult for service providers or the families of the developmentally disabled to bring sufficient resources together to meet the needs of specific individuals. **The Guide to Federal Resources for the Developmentally Disabled** *(5)* lists 104 support programs ranging from income to service to support for planning and coordination activities. This bewildering array of programs is authorized through various provisions of the Social Security Act, Public Health Service Act, Elementary and Secondary Education Act, National Housing Act, Comprehensive Employment and Training Act, Developmental Disabilities and Bill of Rights Act, and Rehabilitation Act. Each of these legislative authorities falls under the jurisdiction of different and often competing committees of the House and Senate in the U.S. Congress, and each is dependent on a multi-layered federal and state bureaucratic structure. Further complication is added by the wide variability of interpretation and usage of these programs by state and local authorities. The sometimes perverse interactions among the programs stand as a warning to well-intentioned persons to resist the temptation of rushing ahead with simple policy change prescriptions. The more sophisticated policymakers and lobbyists know full well that yesterday's reforms are very often at the root of today's problems.

Employment

A major goal for mentally retarded persons living in the community is meaningful employment. It is clearly "normalizing." Work increases the material goods that mentally retarded persons can have. Moreover, it is socially desirable to make productive use of all of our labor force resources.

The vocational success of noninstitutionalized mentally retarded persons is far greater than generally believed. It has been estimated that 87% of noninstitutionalized men identified as mildly retarded while in school are gainfully employed as adults, four percentage points below the norm for all men. In addition, it has been estimated that 33% of noninstitutionalized retarded women identified as mildly retarded while in school are gainfully employed as adults, 12 percentage points below the norm for all women *(2)*. The employment record for mildly retarded women should not be interpreted as reflecting a lower work capacity than that of mildly retarded men. Some of these mildly retarded nonemployed women decide to become full-time homemakers rather than accept the menial jobs that otherwise have been available to them.

These conclusions are based on the results of 27 follow-up studies, most of which reported substantial lack of employment among mentally retarded persons. This, however, was an artifact of how the data were collected and analyzed. Most of the studies were conducted within one or two years after the mentally retarded persons left school, when most were teenagers. Their earnings and employment were low, but so were the employment and earnings of all teenagers. When the data were properly analyzed according to different age and sex groupings, the earnings and employment records of mentally retarded persons were found to rise rapidly as they reached their early twenties.

These findings refute the generally accepted

belief that limited intellect decreases employability. The range of jobs in industry is vast, and there are many jobs within the capabilities of mentally retarded persons. The main problem is to ensure that they are provided with the opportunity to work.

Meaningful work, however, means work that is stable and pays a living wage. It does not include jobs in workshops or activity centers paying minimal wages. Sheltered workshops or activity centers should not be relied on to provide suitable work. They incorporate too many traits that promote inefficient operation. That is, they are often too small, are not business oriented, and do not have sufficient skilled labor to combine with unskilled labor.

Too often the low earnings of sheltered workshop and activity center clients are ascribed to their inability to work, whereas the inherent inefficiency of the workshop or activity center is what often causes the poor productivity. Robert Haveman's study *(4)* of sheltered work in the Netherlands drew sharp reactions when it showed that providing sheltered work opportunities to an increasing segment of the working age population was costing on the order of 7,500 to 10,000 Dutch guilders (U.S. $3,000-$4,000) per participant year. The validity of sheltered work as a vehicle into competitive employment can be questioned both in terms of costs to the taxpayer and benefits to the mentally retarded individual *(6)*.

Meaningful work can usually be found in regular employment channels, although some degree of special accommodation in terms of supervision or work arrangements will sometimes be needed for mentally retarded persons. Yet, pessimistic attitudes are often displayed toward the work potential of mentally retarded persons by many professionals. If this pessimism relates to the inability of many mentally retarded persons to engage in meaningful work, it is unfounded. If it relates to the generally poor programs that this country has developed to place severely handicapped persons in meaningful jobs, and negative attitudes of private and public employers, however the pessimism is unfortunately well-founded.

The question is often raised about whether it is desirable to employ mentally retarded persons if there are non-mentally retarded persons also seeking work. If there are both mentally retarded and non-mentally retarded persons seeking work, the logical solution is to create jobs for both groups. The number of jobs in our economy is not immutably fixed; they can be increased through appropriate fiscal and monetary action. The Full Employment Act of 1946 laid the responsibility for maintaining full employment on the federal government. If the federal government through ineptitude or deliberate choice fails to expand the number of jobs, the disadvantaged segment of our population should not be made the scapegoat of such actions.

It has been asserted that we may some day become so affluent as to render the productivity of mentally retarded persons redundant. This is idle speculation, as there are many reasons to doubt this optimistic forecast. Also, we must act on the present and not the future. There can be little question that any increased output should be welcome in a society that restrains social programs because of inadequate resources, pays minimal social security and supplemental security income benefits and complains bitterly about the level of taxes.

Although some mentally retarded persons would prefer not to work, as do some persons who are not handicapped, mentally retarded persons have the same responsibility as anyone else to work and contribute to their own maintenance. If work provides very meager earnings, however (in some activity centers earnings scarcely cover the costs of going to and from work), then it is not at all clear that work should be compulsory. Work that has only symbolic meaning for some while affording others a handsome living is really a form of exploitation.

The key to good jobs is the development of job opportunities in private industry and government. Although hundreds of millions of dollars are spent on vocational training through vocatinal rehabilitation and employment service programs, we have not as yet developed good job placement programs for severely handicapped persons. Nor have we won general acceptance of the fact that jobs can be developed in regular employment channels for severely mentally retarded persons. The prevailing defeatist attitude is that they cannot do the work.

Government Action

The Office of Management and Budget (OMB) has requested the Secretary of the Department of Health and Human Services (HHS) to develop strategies to reduce costs and to improve the management of services in federal programs that benefit mentally retarded persons. OMB has expressed particular concern over: (a) the size and rate of growth of Medicaid expenditures; (b) the high cost of care for residents of ICFs/MR, particularly in large institutions; and (c) the financial bias in federal programs toward placing mentally retarded persons in unnecessarily large and restrictive facilities. The following are some of the questions to which OMB seeks specific answers:

- What are the costs of providing care for mentally retarded persons in different types of facilities?
- How many mentally retarded persons are there who should be placed in the different types of facilities?
- How many mentally retarded persons are not receiving appropriate care in the different types of facilities?
- To what extent will providing higher quality care and support services in less restrictive settings at public expense induce increased demand for care and services?
- How can the costs of care in large ICFs/MR be controlled?

The OMB also wants to examine existing high quality state programs, particularly the success of New York and Minnesota in moving mentally retarded persons into small community-based residences and into competitive employment.

The OMB is considering several financing alternatives including: (a) permitting or even mandating Medicaid coverage of case management, day care or habilitation services for Medicaid eligible persons not residing in ICFs/MR; (b) providing federal financial assistance for services to mentally retarded persons through some program other than Medicaid; and (c) developing a whole new approach to funding community-based services to mentally retarded persons, such as through a capitation system which would pay a predetermined amount for each person receiving care. While the attention of OMB is welcome, we must be circumspect if we are to avoid building still another set of "pigeon holes" into which people and dollars are poured in the name of normalization or any other shibboleth.

The federal government is involved in other related research and evaluation activities. The Office of the Assistant Secretary for Planning and Evaluation of the Department of Health and Human Services (HHS) is conducting studies to evaluate the results of deinstitutionalization into an alternative living arrangement. One study will document the outcomes and costs of deinstitutionalization at Pennhurst State School and Hospital. Another study will examine the adequacy of care and services given to mentally ill, mentally retarded and aged persons in board and care homes in 10 states.

In cooperation with the Department of Housing and Urban Development (HUD), a major evaluation is being undertaken by HHS of subsidized housing for chronic mentally ill persons. In this demonstration project, Medicaid funds (under a grant of waivers) will pay for both supportive services and access to all needed services in the surrounding community. Emphasis will be placed on "normalized" or "off-site" consumption of services. The evaluation of this approach will estimate the tangible and intangible benefits in order to compare them with the costs of providing combined housing and services.

As part of a broad study of training and employment services for handicapped persons, both the service and housing needs of the handicapped population are being examined. The study will describe the character and types of services likely to be needed by major categories of disabled persons, the resources needed to support them and the funding potential under existing programs. Recommendations for program changes will be made where indicated in order to provide more appropriate sources of funding where current sources create disincentives to the development of least restrictive care and/or independent living arrangements. Finally, a project is being funded to ascertain the feasi-

bility of conducting a large-scale study of private employers with the ultimate purpose of finding ways to open more job opportunities for handicapped persons. When all of these research and evaluation studies are completed, the federal government will be better able to make policy choices to improve the community living and employment options for mentally retarded persons in the United States.

Summary

There are a number of reasons why we are concerned about how normalization will develop in the 1980's. Elizabeth Boggs reminds us that public policy is made by many kinds of people and its raw materials are values, soft and hard facts, and political and other contingencies *(1)*. Unfortunately, few "hard facts" about normalization and its practice are available. Hence, "soft facts" (e.g., hunches, over-simplifications, extrapolations from inadequate data) and political contingencies, are likely to prevail in influencing policymakers to vote yea or nay in matters relating to normalization, deinstitutionalization, and least restrictive care.

Public and private resources available to support and help developmentally disabled persons are limited, and entail opportunity costs which prevent attainment of other beneficial social goals. These opportunity costs and the usual competition over the use of scarce resources evoke arguments against investing in normalizing programs. Antagonists will undoubtedly question the cost-effectiveness and cost-efficiency of making facilitative changes in law or regulations. We have already witnessed state officials defending themselves against class action suits or hedging promises to comply with court orders by pleading the unavailability of funds. These same officials also rationalize delays in promised implementation of court orders on the basis of their unwillingness to see developmentally disabled persons "dumped" into inadequate or nonexistent community programs.

Against such rationalizations, protagonists can be expected to fret over the failure of government officials and the public to comprehend that economic rationality dictates that investments proceed at the margin and continue as long as benefits exceed costs. They will argue that when constitutional rights are involved, these rights are, by definition, the greatest possible good and therefore deserving of the fullest investment. By this logic, "normalization" could be accorded the status of a constitutionally protected right, deserving of the highest priority in public funding decisions.

More than information or even "hard facts" is needed, however. There is a great need for the political will to act. Hopefully this can be achieved through the concerted action of professionals and other constituencies who share the desire to see the normalization of mentally retarded persons.

References

1. Boggs, E.M. The making of public policy: What others do with what we say we know. In **Birth defects, original article series** (Vol. 12). New York: Allen Liss, 1976.
2. Conley, R. W. **The economics of mental retardation.** Baltimore: Johns Hopkins Press, 1973.
3. Datel, W. E., Murphy, J. G., & Pollack, P. L. Outcome in a deinstitutionalization program employing service integration methodology. **Journal of Operational Psychiatry,** 1978, **9** (1), 6-24.
4. Haveman, R. H., **A benefit-cost and policy analysis of the Netherlands social employment program.** Leiden, Holland: University of Leiden, 1977.
5. Litvin, M., & Russem, W. (Eds.). **The guide to federal resources for developmentally disabled, 1977.** Washington, D.C.: Federal Programs Information and Assistance Project, 1977.
6. Noble, J. H. Rehabilitating the severely disabled: The foreign experience. **Journal of Health, Politics, Policy and Law,** 1979, **4**(2), 221-249.

Participant Discussion

MS. KAPLAN: I predict that at some time in the future consumers are going to verbalize their discomfort with our attempts to give them economic choices. I think that sometime in the future consumers will organize and unionize. I also think that it will happen in conjunction with some legal action, because people will say they are not getting paid anything. I think that we are then going to look foolish because we will have to say that we wanted to give people a normal task, but we could only pay 12 cents an hour.

I'd like to know, first of all, if unionization and legal implications started hitting the sheltered workshops, would we lose them because they wouldn't be able to pay normal wages? Second, does it matter if we lose them? Third, if the writing really is on the wall, what are we going to do about it, if anything?

MR. CONLEY: When you talk about sheltered workshops being the next target for legal action, understand that's in the context that there is a feeling among some people that you shouldn't be increasing the number of people you place in sheltered workshops making 12 cents an hour. Rather, we should be trying to open up jobs in regular employment channels where the productive potential is so much greater and the work is meaningful. Work at 12 cents an hour or 25 cents an hour or 50 cents an hour is not meaningful. It's only in this sense there is some question about sheltered workshops.

MS. KAPLAN: I can't speak for all the states, but in Oregon we are fighting for more sheltered workshop slots. We spend all our time fighting for them. People think we need something for these people to do.

MR. MARCHAND: Can I interject one thing? Let us be clear about our terminology. No one who is employed in a sheltered workshop is earning 12 cents an hour, because by definition, sheltered workshops must pay their employees at least half of the minimum wage, which is now $1.55 an hour. So when you talk about 12 cents an hour, you must be talking about work activity centers. There is a difference, a big difference.

MS. SCHAAF: But not all of the people that are in sheltered workshops are able to make that amount. A lot of people that I know don't even get half of the minimum wage.

MR. MARCHAND: Well, they are not in sheltered workshops.

MS. SCHAAF: They are in sheltered workshops.

MR. MARCHAND: They may call them sheltered workshops, but the license the labor department gives them is not for a sheltered workshop. It is a work activity center, and there is a difference.

MR. CONLEY: A few years back a law was passed that required sheltered workshops to pay one-half the minimum wage. Those that couldn't pay this wage were to be designated as work activity centers. So half of these facilities that were once called sheltered workshops promptly called themselves work activity centers. This has led to the ridiculous situation where one side of a shop is an activity center, and the other side a sheltered workshop. You still have people in facilities that are work oriented that are making miserable wages. Are they making miserable wages because they can't produce (which I don't believe), or because the workshop is small and oriented towards single-types of disabilities and incapable of providing the type and amount of work that enables clients to make a meaningful wage?

MR. MARCHAND: That's why the crisis is coming.

MR. KRAUSE: Unionization is a two-edged sword. On the one hand, blind and deaf people and others have been bringing legal action. The Wall Street Journal and others have indicated the problems and indicated what the blind particularly feel about the problems of working in workshops. But, 56% of those employed in workshops today are mentally retarded people.

Regarding the union question, we have been doing a quick study around the country on unions, particularly as they deal with the insti-

tutions. In certain parts of the country, particularly where unions have had long-standing involvement like the New England states, they are today influencing the policy and the operation of the institution more than they have in the past, because the management of these facilities has been subjected to heavy demands of union personnel. They cannot fire people. They cannot manage their operations without the consent of the unions. I am gravely concerned for the future about how much union influence will dictate policy and maintenance of some of our public residential facilities.

MR. CONLEY: Let me emphasize one thing, Fred. I'm not arguing that there are not some good workshops, but I would argue there are a great many that are poor. One thing you could argue for is to get rid of the poor ones and replace them with those that are more business oriented.

The second thing is that there is a big difference between a workshop that's training a person for eventual job placement and one that's keeping a person there indefinitely and making no efforts to place him/her. Anyone can earn one-half the minimum wage in private industry, unless they have a serious behavior problem.

As far as the issue of unionization, remember there are limits to what unions can do. They can't take what's not there. If the productivity is not there, they can't force wages to the point where people won't be hired, and usually unions are not totally irrational. One thing unions might do and what they typically do elsewhere is to have a voice in the working conditions, which would be extremely valuable, I think.

MS. KAPLAN: My concern is that I think that institutions are having a difficult time justifying themselves to the legal inspectors at this point, and it's my guess that this will also be the case with the vocational services that we offer. If the people working there start saying they want a union, then the legal people will become reactive to that, and I can see where we might wind up in the same boat as we did with deinstitutionalization. The legal people will represent the consumers and will point out that consumers work hard, have no choice in the kind of work they do, are being taught work that can't be translated into employment, that they are not being placed into competitive employment, that the conditions are dangerous, that consumers are not adequately paid, and on and on. Will we be able to justify the workshops?

MR. NOBLE: Why should you want to?

MS. KAPLAN: I'm asking this question.

MR. CONLEY: Incidentally, if a workshop really is that bad, it really shouldn't be justified.

MS. KAPLAN: The lawyers, though, will be saying that a mentally retarded person cannot be given workshop as employment unless x, y, and z happens, which may just rule out workshops, and then where will we be? We are already in a fix with residential services and the law. We are going to be in a fix with vocational services and the law, and that's the economics for the person I am talking about.

MR. CONLEY: Somehow I just can't see it getting to that point, but maybe I am missing something.

MS. KAPLAN: I didn't think we would see the residential services getting to the point they did, either.

MR. FOSS: Recently I saw some figures on what the placement rate is out of workshops. If the people in there are training for competitive employment, there aren't many of them finding it. It seems to me that if all these things are wrong, it could be a place for consumers to be pushing for some action.

MR. KRAUSE: You have to understand the type of placements that are going into these type of facilities. It has changed over the years. The workshops today are serving a population of clients which has no prior work experience. It is questionable as to how much training they can undertake in the setting that a workshop provides. Personnel in those workshops are unprepared and generally not well trained for providing job skill training to a group which

is basically severely, and in many cases, multiply handicapped. I have seen some places where all the young man could do was hold a paint can and spray it. If he were asked to do anything else or if you tried to train him, you would have serious difficulty. But, we are finding through Tom Bellamy's studies and those of others, that this happens because we don't know how to train these people. Mark Gold and others have done some exceptionally fine work, and we haven't been able to properly disseminate enough of this information and train people in the workshops to be able to use what are possibly better methods of training in that environment.

MR. FOSS: My comment is not to suggest that the purpose of consumers looking at these workshops is to put them out of business. I know from my experience in in-service training that workshop people don't get trained nearly as much as a lot of other groups, but something has to happen to get that started.

MR. KRAUSE: This is a serious problem. At one time we had at least five universities in this country which trained workshop personnel. To the best of my knowledge, today we have two, possibly three. I know San Francisco is, and I think DePaul is still doing it. I don't know if Rutgers is any longer.

MR. LITVIN: We have one in Greeley.

MR. KRAUSE: There was a funding source for the training of workshop personnel, and through economic cuts, the amount of funds for that kind of training has declined over the past few years.

MR. NOBLE: I'd like to get back to the basic question here. What are we talking about, economics and normalization, or are we trying to justify what in the hell we are now doing under certain constraints?

I went across the seven northwestern European countries on a study I did a few years ago. I talked a great deal to economists about sheltered work provisions for the severely handicapped and got a pretty good idea of what they think they are trying to achieve. I think the public policy question comes down to this: If you have an objective to achieve certain transitions into unsheltered, unsubsidized employment and that program fails, then you have to decide what function, what benefit, that particular program serves. When you look at the overhead for maintaining those workshops and you think about distributing that overhead in terms of cash payments to the workers, I think you could pay them a much, much higher wage for just staying home doing nothing.

There is a demonstration model being run by the Department of Labor and they have estimated that the overhead per prson is between $9,000 and $12,000, compared to about a $6,000 overhead in training job corps participants. So we have got some question of who benefits and who pays here.

MS. KAPLAN: Well, the courts say . . .

MR. NOBLE: Well, the courts will raise hell, of course, especially when they find, as Claude Whitehead did in his analysis of the Department of Labor's own studies, that about 20% of the regular workshops classified as such (not as work activity centers) were paying less than one-half of the minimum wage. One of the major recommendations from those studies was that the Department of Labor begin to enforce compliance with the Federal Minimum Labor Act.

MR. MARCHAND: Just another reason why I was arguing with Gunnar earlier about the Labor Department not being a whole lot better than any other Federal agency for enforcing these programs.

MR. KRAUSE: Then we could say, as we did in our discussion of Title 19 and the Medicaid ICFs/MR funding, that sheltered workshop programs are not enabling our policymakers to pursue a normalization program. They are possibly disincentives to normalization more than incentives to normalization.

MR. NOBLE: If these workshops are not producing what they say they are, and we are playing games, trying to get some bucks from Rehabilitation to keep people in work activities because it's considered good for them, then we are doing this under the table. What we should be trying to do is identify that problem to see if the activity is justified. If it does not result

in transition into unsheltered employment, then we call it occupational therapy. If that is something that is good and desirable for a certain portion of the developmentally disabled population, and it promotes better feeling about themselves and normalized behavior, then I think it's legitimate and should be funded as a legitimate activity.

MS. KAPLAN: That's right, but from the consumer's point of view, they are hearing and they are told every day that if they go to work at a workshop or activity center they will learn how to work and be put in a job soon and out of this program. Imagine what it's like from their perspective, because it isn't working and it isn't their fault.

MR. SOENNEKER: In terms of the future, I suspect that we will get approximately the same amount of money to do the job well for everybody that we now get to do the job poorly for some. What I am trying to say is that as we look at alternatives to do the job that needs to be done in the future for the mentally retarded, I think we are, in fact, not talking about a massive infusion of new resources. If we keep up with inflation we will be lucky. If we are unlucky, we will be in California's position of a 25% reduction. So I think it really becomes critical to begin to talk about alternatives. How are we going to do the job that needs to be done through re-allocation of resources rather than a massive infusion of new monies? It's at this point where the more long-range human systems management (not human management but the management of human systems) really begins to take on a critical priority. We have got to learn how, for example, to analyze our budgets, not in terms of a one-year cycle, but in terms of long-range savings in the system. It's these kinds of issues we are going to have to struggle with, because I think we are naive if we believe that we will have any major new expansion money, beyond keeping even with inflation.

MR. MARCHAND: That leads me to where I was hoping we would be towards this time of day in the area of economics, and that is systems change and getting bucks and the potential for dollars. I have to approach that from my own day-to-day perspective, which is dealing with the United States Congress. There is no greater frustration when one thinks about systems change than looking at how the United States Congress treats handicapped people in their programs.

When I think of any potential solutions to the myriad of issues that have surfaced over the last couple of days, it absolutely boggles my mind to think that we have an inkling of a chance to make changes in Congress, based on the jurisdictional issues that we will have to face and the enormous job of education that we would have with these powerful individuals who run the committees.

We have an entity in the United States Senate called the Subcommittee on the Handicapped. Now, one would think that that would be the committee to go to to discuss many of the issues that we have discussed today. As a matter of fact, the Subcommittee on the Handicapped has jurisdiction over less than **15%** of the Federal dollars that somehow or other get funneled out to assist handicapped people. There is no way that we can deal with these issues through a systems process without dealing with these people who hang on to their jurisdiction and territory. Just how do you get Russell Long, Ted Kennedy, Harrison Williams and at least two or three other people to sit down at a table like this and talk about those issues? Then, if you are successful, you have a bigger problem in the House. Then it's got to all come together. We have enormous, enormous difficulties.

I would advocate today that we have absolutely too many programs for the handicapped

already enacted by the United States Congress and I'm damn well part of that problem. It's my job to do this. It's never been more evident to me than it is today, because I spent two full days last week analyzing the President's budget, and would you believe that there are at least five programs authorized in the Rehabilitation Act Amendments of 1978 that don't even exist in the budget. They are absolutely zero funded three fiscal years after the program was authorized. The handicapped community and their advocates have so many programs to worry about that we can't even go out and get the money for them anymore. It's the truth.

I attempt to bring together the Washington handicapped community to try to evolve reasonable priorities for appropriations for these programs, and we try to allocate leadership roles to certain organizations who have vested interests in some of these. We flat ran out of leaders. We ran out of organizations, and we ran out of interested people who are willing to go out and fight for a particular program.

An example is the Community Services Employment Program out of Rehabilitation that is supposed to be administered by the Labor Department. I have yet to hear a single handicapped individual or organization representing handicapped people address that program from a money standpoint, and yet that law was put in place in 1978. The President has put no money into it and will never put any money into it, and probably the next President won't put any money into it because there is nobody to advocate for it. That's how far afield we are.

The biggest problem we have is congressional jurisdiction, in my opinion. We can't get past that. It's something that has evolved. It hasn't, by any means, been shaped through a sound public policy perspective. It has been an incremental process that's been made to evolve. If there is a little problem, we solve it with a band-aid. If there is another problem, we solve it with a much bigger band-aid. If there is another problem, we solve it with a smaller band-aid and on and on and on. I don't know that we are capable as a society today to solve the problem. I don't know that we are all ready to do that yet, certainly the Congress isn't ready to do it. It's absolutely not ready. In fact, in my opinion, it will resist most of what we try to do. If we are successful, it will take years, maybe decades of education.

MR. KRAUSE: Paul is completely accurate on that. It's extremely frustrating for him, and he's extremely knowledgeable about these problems. The few Congressmen who do know something about it are in a position where they can't do one hell of a lot about it themselves, or they don't have enough seniority or they are not on the right committee, etc. I think we can start off with Paul's comments about system change because that's where I think we should be able to try to address some kind of recommendations to this or to other groups. One of the system changes which I don't think has been given enough consideration and thought is how possibly brokerage systems could be applied. Mark Litvin, under a contract with NARC, put a Federal resource guide together. But it is such a multitude of resources, and yet funding is at a scarcity, or people are not aware of how to reach those sources. That's where I think some form of a system change along the lines of a brokerage, which is being today very seriously considered for aging, could also be applicable for programs for developmentally disabled people.

MR. SOENNEKER: Let me comment on Paul's point a little further. In preparation for putting together a proposal to the United Way, I did some study that I think follows up on some of the things that Ron did a number of years ago. That is, when you start adding together all of the various federal programs, state programs, local programs, and so forth, you are talking about a heap of money that is spent on this group of people in this country.

MR. KRAUSE: Over three billion.

MR. SOENNEKER: How much?

MR. KRAUSE: Over three billion.

MR. MARCHAND: That's only federal.

MR. SOENNEKER: By the time you add it all together, if our state parallels what is happening nationwide, you are probably talking about something on the neighborhood of 20 billion dollars a year minimum.

MR. KRAUSE: Spent on handicapped people?

MR. SOENNEKER: No. Spent on mentally retarded people, including in that those people who have traditionally been considered the DD population. You are talking about all your special education money, SSI and on and on and on. The amount of money from the federal budget alone goes considerably above three billion dollars by the time you add it together. Now, that's a heck of a lot of money, but it's in such diverse programs that if we had that money to do with what we wanted, rather than playing all the hoops and circles, I have a strong suspicion that we would have the resources to do the job right for the handicapped. To me, the ultimate problem we are struggling with is how do we get that combined federal, state and local system turned around to a point where it can have an effective impact on the handicapped.

MR. NOBLE: We never have enough money to do all of the good things we want to do. Most of the good things we can defend, as to their effects. It really comes down to trying to understand what goals we have, what we want to achieve for handicapped individuals and then using our resources to achieve those things.

When the uses of resources are not productive, they should be curtailed and the money spent on those sets of activities that are delivering goods. We do not seem to have a system of accountability. That partly, I guess, is our inability to manage. But we do not have a system or ethic that forces us in that direction in the public sector. We never go out of business.

MR. COOKE: Well, I think part of the problem is that what we are doing is very difficult to measure. I think it's easy for the economists to demand accountability, but accountability of results is very difficult to come by.

MS. YARON: Well, not really. In the last three years the Bureau in our region funded a series of contracts to the tune of a million dollars to come up with what is called DDS, Development Disability System, that would cover both process and outcome accountability. It was done with good reputable research outfits and with a representative body of experts from DDS that served as advising panels. The problem was that it was limited by the DDS to the former grant moneys, and when the states were requested to come up with a plan and a design to meet the specifications and criterion of this system, the states said that they didn't want that kind of accountability because it was too costly for overall programs.

MR. COOKE: But what I am talking about is a very selective program. For example, for over five years the Kennedy Foundation has been trying to give away some of its money to University Affiliated Facilities to carry out comparative cost-benefit analyses at different modality levels. We know that there are literally billions being spent in certain rehabilitative approaches without any documentation whatsoever that any of them accomplish a damn thing. Certainly there is very little evidence of one approach being superior or inferior to another. They all go on. They are all funded. They are part of the cost reimbursement formula, and so forth.

I have been trying to get the National Institute of Health to support this. I hope that the new Institute of Handicapped Research (for God's sakes we must change that name, it's hard enough to do research without doing handicapped research) might be able to do it, but we must do it with certain selective approaches. But, both the investigative and the funding communities put these things at very low priority. The National Institute of Health thinks it is just ridiculous for the investigators to spend their time finding out whether or not one way is better than another way.

MS. KAPLAN: If you are ever interested in having the consumer look at what the services look like, we have a few People First members here. I mean, you talk about giving away money to a University Affiliated Facility to research services. I'm just saying that maybe some money needs to start going to the consumers.

MR. COOKE: I'm all in favor of putting purchasing power in the hands of the consumer. I

think that's very important. On the other hand, you have got a lot of treatment modalities going with very little in the way of analyses of benefits in relationship to costs.

MS. KAPLAN: Yes, but you can ask the consumers if they think they are getting what it is we think we are giving.

MR. COOKE: Well, you can do that, but you have to do both.

MS. SCHAAF: But I think, Bob, that if you don't want to give money to the consumer or to any other program or club organization, you are building a fence of ignorance to these people. You're wanting to ignore them and look to others that you can dwell better on and forget about those people.

MR. COOKE: I'd like to give the handicapped purchasing power. They don't have it at the present time. That's the free choice principle that we talked about earlier. The second thing that is needed, however, is a better identification by professionals of what's good and what's bad in terms of product, in terms of results, so that the consumers have a choice as to whether or not they want to spend their money on something that doesn't do much for them. For example, in the medical area, it is possible to buy vitamins that cost a buck a capsule, and you can buy others that cost probably a penny. The dollar ones might be better, but if you do some investigation, you will find the dollar ones don't do a bit more for you than the penny ones.

MS. SCHAAF: So you think it's a waste of money.

MR. COOKE: Many of these things are a waste of money, and the consumer ought to know about that. Even the professionals don't know it's a waste of money because nobody has bothered to look at the problem in medicine. We do it all the time. We introduce all sorts of new treatment approaches without ever finding out whether they add anything at all to the well being of the patients. They are all accepted right away and the government agencies go on paying for them on a cost reimbursement basis. Bills just get higher and higher with very little evidence as to whether anything more is being accomplished.

MS. YARON: By what authority are you going to ask the states to show you where the money goes?

MR. COOKE: I'm not asking the states to do anything. Take Medicaid for example. Before Medicaid should pay for some new activity or procedure, there ought to be evidence that the value added will be commensurate to the additional expense.

MS. YARON: But it has to be provided to the funding source by the states. How are you going to make the states do it? By telling them if they do not, you're not going to provide the money?

MR. KRAUSE: You could take some pilot programs from certain chosen areas and depart from the traditional way of doing things to see if new ways are more effective. One of my concerns is administrative costs. I think those who are today supporting Proposition 13 and other such efforts are fed up with government waste that's going to high salaried administrators. They see it when they go to welfare offices. They see it when they go to unemployment lines. They see it as they go to the various facilities and institutions for the mentally retarded. This is where they are wanting to cut.

I think we need to choose a few areas, abandon the traditional way and start over. The assistant federal evaluator could very well take that as a serious recommendation and pilot some new studies that would probably be cost-effective in savings, studies that aren't being done today in any other manner.

MR. CONLEY: I'd like to make one comment about the problems of defining operational goals. It's difficult. It's also possible. It may take ten years, but it's better to start than to spend the next ten years saying how difficult it is. If we spent some time defining operational goals, we wouldn't have to worry about what normalization means, because it would fall right out and possibly quite a few of the other problems we are talking about would begin to settle out as well.

MR. NOBLE: The accountability system we are talking about is a difficult task to undertake, but consider where we are today. Paul hustles the Congress. He looks at a bill in terms of whether it's likely to draw more money for the mentally retarded. A lot of us who analyze inside HHS believe in funding handicapped programs or programs for the mentally retarded. Yet, we don't know what's really going on with the funds that are being spent. When we do special studies we are finding that very, very little is going on that is productive in the sense of accomplishing the goals which are embedded in the legislative intent, and we are not satisfying the consumers.

So how do we play this game? Do we begin to investigate by getting a few professionals to take some of the dollars the Kennedy Foundation has offered, or do we just continue to vote with our hearts and for our interests, and fall further and further behind with respect to achieving the goals of normalization?

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Advancing Your Citizenship Publications

An Advocacy Manual for Persons with Disabilities

A manual intended to assist disabled persons in exercising their rights of citizenship. Presented in a question and answer format, it is expressly written for handicapped individuals, their parents and their advocates. The first section on **Legislation** covers the three major federal acts which have direct implications for handicapped persons and their advocates in terms of obtaining a broad range of services to which they are entitled. The second section on **Consumer Protection Mechanisms** includes the major types of protection required by federal legislation. Individualized Program Planning, Non-Discrimination, Least Restrictive Alternative, and Procedural Safeguards in Education are "tools" with which disabled persons and their representatives may advocate for services and equal opportunity. The final section, **Case Studies,** demonstrates the interpretation of federal legislation and the application of consumer protection mechanisms in terms of real-life problem situations. (78 pages)

An Annotated Bibliography on Consumerism/Advocacy for Persons with Disabilities

A comprehensive bibliographic document comprised of 289 references on consumerism/advocacy drawn from over 100 different periodicals, books, monographs, reports, and proceedings. Covered are a wide range of topical areas as reflected in the subject index, e.g., **consumer involvement/client participation, civil rights/legal rights, protective services, self-help groups/organizations, client assistance projects, types of advocacy, individualized program planning, legislation, vocational rehabilitation, public welfare, business/marketing consumerism, research.** Each coded reference is followed by a detailed descriptive annotation. Designed as a working tool for professionals, consumers/advocates, and students of the advocacy consumer movement, this document will direct the reader to a wide range of literature on consumer/advocacy theory, research and practices, as well as a variety of training manuals. (241 pages)

Advocacy and the Developmentally Disabled

A monograph which provides a framework for understanding advocacy as it relates to developmentally disabled people, and conveys the significance of the advocacy movement to this population. It is also intended to assist developmentally disabled individuals, their parents, professionals, and others in becoming advocates. **The five chapters define advocacy, examine its origin and development, discuss federal legislation relating to its evolution and implementation, and outline a model support and advocacy system for developmentally disabled groups.** Current and future trends in service delivery as they relate to advocacy are discussed. (127 pages)

Essays On Consumer Involvement of the Handicapped

A monograph which reflects on the development of consumerism for the handicapped during the decade of the 1970's. Essays in the first section on **The Advancement of Consumer Involvement** discuss and analyze the history of the consumer movement, consumerism practices, the role of retarded people in the consumer movement and issues in need of empirical pursuit. Essays in the second section on **The Emergence of Consumerism Through Congress** address the legislative making of civil and consumer rights of the handicapped. These essays are derived from 57 congressional documents which represent Congress's activities in regard to rehabilitation legislation during the period of 1972 through 1978. (49 pages)